

SUBSTANTIAL CONNECTIONS:
THE TRANSACTING OF HUMAN ORGANS AS A MORAL ECONOMY

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Degree of Ph.D.
University of Edinburgh

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DECLARATION

This thesis has been composed by the undersigned, and is based entirely on her own research work.

Ms Joni Wilson M.A.

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Dedicated to all donor families

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ABSTRACT

Publicly promoted as 'the gift of life', organ donation offers a strong contrast with forms of gift giving familiar to anthropologists, where gift exchange is conducted to create and maintain relational networks. Allowing the removal of one's organs after death, to be transplanted into other bodies for the purpose of enhancing or extending life, is commonly understood, certainly in Britain, as a voluntary and anonymous gesture. It is presumed to entail no thought for any personal benefit and no intention of establishing a relationship with the recipients of one's organs.

Implicit within this understanding of organ donation is a model of the Western person as an autonomous and bounded individual, operationalised in anthropology as an analytical tool with which to contrast 'other' economies of personhood.

This thesis critically re-assesses public and academic acceptance of the popular image of organ donation, and challenges the anthropological model of the Western person, revealing the partial nature of both.

Using ethnographic data from a three year intensive study involving health care professionals, the families of deceased organ donors and the recipients of transplanted organs, a framework is developed within which human organ transactions can be analysed in their entire cycle.

A primary focus on attitudes towards the bodies, and body parts, of deceased organ donors reveals an array of shifting subjectivities. The term refers both to the diverse perspectives held by various categories of participants and to the oscillating perspectives of individual participants, the researcher included.

Studying how human organs circulate undermines the assumption that agency is (only) autoproduktive. Rather less voluntarism is present than popular imagery suggests. Further, a consideration of the relationships within which organs circulate serves to illustrate that the production of self implicates other (non)-selves. What emerges is the notion of connective personhood, whereby donor families and transplant recipients inevitably participate in a self-making social relationship, through sharing the substance of the deceased donor.

ACKNOWLEDGEMENTS

Thanks are due beyond measure to Tom and Catherine, and Rita and Conrad, who allowed me to study their pain and loss in such intense detail and whose personal photographs and memorabilia illustrate this thesis; sincere thanks are also due to the main organ recipients, who must remain anonymous, as well as the other recipients and donor families who provided such invaluable insights into their participation in the transplantation programme; without the assistance of John and Margaret Evans, Jane and David Nix, and Phil Hatton, the late Jo Hatton, and Chad Denby, research would have been seriously curtailed -- in exchange I hope my work may contribute to your own; thanks to the many health care professionals who gave their time to talk about the stresses and strains of their jobs. I am much indebted to many academic colleagues -- to my supervisor, Iris Jean-Klein, whose intellectual stimulation and linguistic rigour is present on every page of this thesis; to Jill Haddow for her unswerving support; to Anne Alnaes, Paul Gill, Glennys Howarth, Tim Ingold, Eleni Papagaroufali and Dimitri Tsintjilonis for constructive critique; to staff and student attendees at the University of Edinburgh's Department of Social Anthropology postgraduate seminars. Research was generously funded by the Economic and Social Research Council. I am obliged to the Department of Health, MORI, Kings Fund Publishing and United Kingdom Transplant Support Service Authority for permission to reproduce statistics; the promotional leaflets Plates 1-6 are Crown copyright material, reproduced with the permission of the Controller of Her Majesty's Stationery Office; the quality of reproduced materials including photographs is due to Ronald Binnie's artistic and pc skills. Last but by no means least, thank you to my family for their love, patience and support.

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SUBSTANTIAL CONNECTIONS: THE TRANSACTING OF HUMAN ORGANS AS A MORAL ECONOMY

Introduction

“[T]he best quantitative measure of the success of clinical transplantation is the degree to which it does not receive publicity, that is, the degree to which we take its accomplishments for granted” (Sir Peter Medawar,¹ cited in Fox and Swazey 1974:74).

In this, the first decade of the twenty-first century, it is technologically possible to remove an extensive range of tissue and solid organs from one body and place them into other bodies, though substantial transplant activity has mostly developed during the last thirty years.² It was only in 1967 that Christiaan Barnard transplanted a human heart, an event which attracted prolonged and global media attention. (Not many people remember the name of the recipient or the donor.) Kidney transplantation has a longer history, but began by using living, genetically related, donors. A little over three decades later, the transplantation of all major solid organs has become standard health care treatment. It is already becoming difficult to remember a time when transplantation was not possible. However, as Illich (1981) has pointed out, rapid and successful advances in biomedicine are liable to generate their own nemesis. Despite having become almost routine surgical practice, or so we are led to believe, and contrary to the statement from Sir Peter Medawar, organ transplantation continues to

¹ Medawar's research into the physiological rejection of skin grafts to treat severe burns made a contribution to reducing the incidence of rejection of transplanted organs.

² For a comprehensive list of these cross-bodily transfers, see Machado 1998:2, Figure 1.

receive a great deal of publicity to this day. The success of transplant technology has provoked a demand for human organs which, at the present time, far outstrips their availability. This contests the public performance of everydayness, or the routine status of the practice, culturally speaking. In fact the publicity is necessary not to prepare people to receive organs, but to encourage organ donation. It is promoted in terms of the 'gift of life'.³

The gift of life is to be given under extraordinary circumstances. Popular understandings of gift giving, it is fair to say, tend to envisage living givers and receivers. But, although transplantation technology currently permits the removal of single kidneys and parts of the liver or lungs from living donors, the majority of organs transplanted in Britain are removed from people declared brain stem dead.⁴ The legal constraints surrounding organ donation in Britain require those who would wish to become organ donors in the event of their death to formally register themselves as donors, a system termed *required consent* or 'opting-in', which involves carrying a donor card or completing an application to the Donor Register. Organ donation is officially promoted, academically debated, and indeed popularly understood as a voluntary, anonymous and altruistic gesture towards others -- a gift freely given to a stranger, with no desire for a return gesture. Most importantly, there is no social relationship envisaged between the giver and the receiver. As if to reinforce the impossibility of any relationship, the giver -- that is the organ donor -- is deceased as a condition of the gift transaction.

³ The reader may assume quotation marks hereafter. Their constant inclusion becomes tedious.

⁴ I discuss the transplantation of the major solid organs -- heart, lungs, liver, kidneys.

However, the present study shows that donor families and recipients find it difficult to participate in this act of giving without relationships being forged or activated; my aim is to account for the disparity between public and academic perceptions of organ donation, and the attitudes held by donor families and recipients.

In doing so, I question the analytical value of a tenacious model of 'the Western person' which we can see reflected in public and academic interpretations of organ donation; a model which also resonates with biomedical discourses on the body. It stems from a persistent political ideology with historically specific roots which represents (Western) people as separate, autonomous, bounded individuals, "linked *merely* by ... relationships" (Bloch 1988:16; cf. Geertz 1983). As a model, it has been operationalised in anthropological studies to present in sharp relief 'other' understandings of bodies and persons (Becker 1995; Strathern 1988). Similarly, discussing the use of human tissue and organs in 'bio-technologies', Strathern (1997) contemplates a Western *individual* which complies with her depiction of Western consumer culture, and one I recognised in public discourses and personal conversations about organ donation and transplantation. Yet it ill-describes *personhood* as I have found it to be transacted in everyday life in Western settings, or so my study of the everyday apprehensions arising from organ donation and transplantation suggests. I shall argue that donor families and organ recipients are inevitably implicated in a social relationship, through the 'inalienable substance' of the deceased donor.

The notion of separate, autonomous, bounded individuals admits of two fundamental assumptions. First, they are the authors of their own agency, freely

exercising choice in what they do (Strathern 1988, 1997). Second, they are the authors of their own selves; who and what they are being shaped by factors internal to their boundedness rather than external for example the activities of other people (Battaglia 1995). Further, the model presupposes certainty about bodily boundedness, “that we know what the boundaries are between one person and another” (Bloch 1988:16).

A study of how human organs circulate undermines the assumption that agency is (only) autoproduktive. Rather less voluntarism is present than the popular image suggests. Further, a consideration of the relationships within which organs circulate serves to illustrate that the production of self implicates other (non)-selves, through “mutable entanglements with other subjects’ histories [and] experiences” (Battaglia 1995:2). In the present study, those ‘mutable entanglements’ produced an array of shifting subjectivities, a term I employ to refer not only to the diverse perspectives held by various categories of participants, but also to the oscillating perspectives of individual participants, myself included.

In strong contrast to the model of ‘the Western person’ I have found the notions of ‘relational personhood’ (Battaglia 1990) and ‘connective selves’ (Jean-Klein 2000; cf. Joseph 1994) invaluable to my understanding of the social complexities of organ donation and transplantation.⁵ Battaglia (1990:188) has “shifted the focus of mortuary analysis away from the dead and their survivors as separate social categories.” Emergent from her elegant ethnography of the people on Sabarl Island is a notion of personhood which acknowledges that “the self [is] defined

⁵ Jean-Klein (2000) *American Ethnologist* 27,1: not printed at time of thesis submission. All page references for this article are based on original manuscript, 53pp.

through an array of significant relationships with others, past and present, living and dead" (Battaglia 1990:188). I am arguing that the connectivity of deceased organ donors, their surviving families and the recipients of their organs goes beyond the secondary place accorded to relationships in the dominant Western model of the individual, thus undermining public, academic and biomedical perceptions of organ donation and transplantation which are predicated upon that model.

Jean-Klein (2000:3) has pushed the analysis of 'self-making' further, to argue that the production of 'self' may actually be located in the bodies of others, which she glosses as "the controlled dispersal of self," illustrated from Joseph's (1994) study of cross-sibling relationships in Lebanon; a girl's "adherence to the female code of morality," in which she is tutored by her brother, is thus an enactment of her brother's effectiveness in exercising interpersonal control, influencing his "sense of himself (and his recognition by others) as 'manly' and 'honourable'" (Jean-Klein 2000:4). In the current research, there are three, and perhaps four, sets of interpersonal relationships to be considered; the issue of 'control' is problematic and one which requires further exploration. Nevertheless, to illustrate the 'dispersed enactment of self' with a forceful example from the current work, I found that donor families' sense of themselves, and more importantly, their ongoing production of the donor's self as socially valued, was dependent upon the extent to which health care professionals and organ recipients concretised in visible form their appreciation of 'the gift' -- acknowledging the central role of organ donors and their families in the entire process. Where appreciation was not performed in this fashion, donor families felt that

they and their deceased relatives were being erased from the landscape of the transplantation programme.

In summary, then, my argument entails rethinking some fundamental, taken-for-granted categories in common, everyday, English language use, interwoven into our commonly held, yet partially understood processes of self-making.

Structural presentation of the central theme

Writing of couples undergoing assisted conception, Franklin (1997:13) comments that her book will make sense when the reader gets to the end of it, unlike the couples she studied, who struggled to make sense of a process about which they had ambiguous and confused perceptions. I offer the same comment. During this research, I found no stable viewpoints or categories, and struggled to find a path through a quagmire of similarly confused and ambiguous perceptions, shifting subjectivities, held by a diverse range of people implicated in giving, waiting for, and receiving, human organs. The bodies and organs within the donation and transplantation process would not 'stand still' to be unequivocally named (cf. Lock 1993:148).

A constantly shifting terrain provokes representational difficulties for the production of a text requiring some structure and logical development of argument. I have partly resolved this dilemma through the adoption of a rhetorical device in the form of parallel but directionally opposite 'perceptual trajectories'. These are not of themselves stable, but sufficient to my purpose. The first trajectory reflects shifting and conflicting attitudes to 'bodies', following an organ donor as he or she moves from life to death, as I argue, from being a loved family member to an anonymous

body, the container of equally anonymous organs. While alive, potential donors might adopt a utilitarian view of their own body; once deceased, their bodies maintain affective significance to their families. In hospitals, intensive care unit (ICU) staff face the ambiguity of caring for a deceased person, alongside the living, while theatre staff must operate on a deceased person. Transplant unit (TU) staff have their own patients in view and, whether they would agree with my choice of language or not, utilise a potential donor's body as a means to an end -- that end being to save their patient's life with a transplanted organ.

The parallel and opposite trajectory follows the trace of an organ from one body to another where I argue that it moves from an anonymous to a personifying object. Its anonymity resides in the public domain, where increasingly strident calls for more organs take inadequate account of the fact that people have to die to make them available, or that those people are the loved members of families who would rather see them go on living. Health care professionals are aware of donors as members of families, though they bring their own priorities to bear on perceptions of organs. Many recipients never know the identity of their donor or surviving family members, but they do exist, for recipients, as people who shared each other's lives and are now separated by death. The "hidden narratives" of those lives and that death (Helman 1991:100) -- what I am calling the donor's 'intangible substance' -- accompanies the tangible substance of the transplanted organ, and is carried within the recipient for the rest of his or her life which, as I shall show, can be equally influenced by both the intangible and tangible substance of the donor.

Excavating the taken-for-granted

The taken-for-grantedness of everyday life is something anthropologists tend to encounter as alterity in the non-Western world of the discipline's primary -- and for many years its only -- research field (Bloch 1988:16). Even when the anthropological gaze was turned back on itself, to studies in the Western world, the preferred focus was "distinct and often marginalised groups" (Okely 1996:5). Contrastively, Okely's work has sought to reveal 'magical credulities' and 'fractured constructs' residing in Britain's wider, dominant society and of which their holders are unaware. Bourdieu (1977) described this lack of awareness as 'practical mastery', in effect "a learned ignorance ... as to the generative principles, or sources, from which [one's] cultural style derives" (cited in Hockey 1990:17). Thus the concepts and practices comprising in general terms 'the British way of life', are taken-for-granted, until one is forced to confront their inconsistencies and tensions.

A similar argument could be made regarding anthropological notions of 'the Western person', which must be homogenised to assist cross-cultural comparative enterprises (Strathern 1988; Becker 1995:2-4). Primary features of this model are its "independence, autonomy, and differentiation" (Marsella 1985:290), "anchoring the self to a body" (Becker 1995:4). While alluding to its "propensity to stereotype" and possible lack of fit with ethnographic data, Becker (1995:4) justifies her own use of this 're-ified folk model' as "a reasonable substrate for inquiry into how self representations ... inform embodied experience" in Western and Fijian contexts. As an analytical tool, the model of the Western person can certainly be identified in particular contexts in Britain, as Strathern (1997) has shown in her discussion of 'bio-

technologies'. Becker (1995:3) suggests that "Western folk models provide insight into culturally particular representations of selfhood that identify core cultural values." In Britain, too, representation of 'the Western person' as autonomous and bounded is culturally particular. In the context of 'bio-technologies' it illuminates core cultural values such as freedom of choice and individual rights, along with the 'successes of organ transplantation'. These values jarred glaringly for many of my research participants when starkly juxtaposed in their actual involvement with organ donation and transplantation.

It is the clinical practice of organ transplantation itself which creates and maintains this tension. In 1973, Baudrillard (1973:126) proclaimed "Today, it is not normal to be dead ... nothing else is as offensive as this [and consequently] the dead have no place." Whatever its veracity then, three decades later the statement is not entirely accurate. Biomedical science certainly regards death as a problem to be removed (Illich 1977:113) and will go to extraordinary lengths to do so, one of which has been to provide a very useful place for the dead as containers of replacement parts for the living. Even for the bereaved family, organ donation is supposed to take the sting out of death, or so we are led to believe; promotional materials make a point of suggesting some comfort may be derived from knowing other lives have been saved. And since the body and its parts would only go to waste anyway, buried or cremated, how can anyone object?

Let us ask, instead, how did we get to here? Barely a century ago, the use of bodies for the advancement of science was considered anathema (Richardson 1996). Even half a century ago, the possibility of transplanting human body parts was found

only in the realms of science fiction (Helman 1991) and mythology (Doniger 1996). In the 'bio-technologies' of the twenty-first century, bodies and body parts are "the substance of people's interactions" (Strathern 1997:298). Today, refusing to permit the removal of organs may be regarded as anathema; "the moral worth of giving [and] the heroics of saving lives" (Lock 1996b:164) forms a compelling model of socially approved behaviour.

Its normalisation, heroism even, does not mean the transplantation of tissues, organs, even visible limbs, from one body to another has entirely lost its horror aspect (Youngner 1996). That the practices remain within these literary realms suggests a persistent degree of astonishment and ambivalence towards them, to say the least. Such ambivalence is also apparent with regard to the redefinition of death on which organ transplantation is predicated.⁶ Professional and lay people may hold deeply ambivalent views when actually confronted by the body of someone declared brain stem dead, or the possibility of physically incorporating a major internal organ from a body not long before considered equivalent with a person. How people manage these extraordinary mental leaps and actual cross-bodily encounters is a moot question in its own right, and answers are bound to unsettle what are historically taken-for-granted notions of persons as bounded and autonomous units.

A society's dominant and widely acclaimed values and beliefs need to be experienced as unquestioned and enduring (Hockey 1990:28, citing Hertz 1907)). Yet, as the tensions and ambiguities inherent within the practice of organ transplantation demonstrate, "The events through which we live are forever

⁶ On the validity of the definition see e.g. Lamb (1985) and Evans (1994) or Keep (1998) and Gill (1999).

outrunning the power of our ordinary, everyday moral, emotional and intellectual concepts to construe them” (Geertz 1968:101). Our unquestioned and enduring values then are more like work in progress. In struggling to defend them, we make them, and I would argue, in life and death situations, we catch ourselves making them.

The process of organ donation and transplantation as I encountered it resonates with some of the discipline’s prominent theoretical interests: exchange systems, the politics of relationships, the conceptualisation of individuals, persons and bodies, the inter-relationship of moral values and social actions, interpretations of death and mortuary practices. Anthropology is aptly suited to investigate the dramatic metamorphoses of taken-for-granted notions, as one moves beyond what I shall call the ‘public performance of organ donation and transplantation’ (see Battaglia 1990:188-199 for a lucid synopsis of the performance of *segaiya*), to the actualities of participation for organ recipients and the families of deceased organ donors.

On that note, ‘the performance of organ donation and transplantation’ is interchangeable with ‘participation in the donation and transplantation process’. By ‘public performance’ I mean an emergent aesthetic presented as ‘this is what we do’, an idea of what involvement in the transacting of human organs ‘is like’. It is derived from various sources, and broadly shared by large numbers of the population, but it is nevertheless contestable as a result of actual participation. Within these performances, language use ‘directs’ our understanding of what is going on, presents particular ways of participating in, or assimilating, events. To illustrate my point, I offer two key examples from my research.

The term 'gifts' applied to human organs made available for transplantation is used in this text for convenience rather than analytical accuracy. Western understandings of 'gifts' are intimately bound up with the representation of organ donation as voluntary and altruistic; further, human organs must not be treated as commodities to be bought and sold. As I will make apparent, the extent to which human organs are gifts is open to question yet no other adequate terms appear to be available. 'Donor' and 'donation' are susceptible to the same argument (cf. Machado 1999:57-61) but are also used here for convenience.

The common term used to describe those who have received an organ from another body is 'transplant recipient'. Note how attention is drawn to the *procedure* of transplantation and by implication its practitioners, rather than to the *substance* being transplanted which draws attention to its origin in another body, now dead. My preferred choice of term is 'organ recipient'. Fuller discussion of the impact of language use in the performance of organ donation and transplantation is taken up in Chapter Three.

Placing the Researcher

Conducting research with bereaved people or those who have been forced to confront their own mortality and now live 'on borrowed time', as one organ recipient phrased it, is emotionally demanding and this intensified my own sense of involvement in the lives, and indeed the deaths, of ... I find myself hesitating here. 'My informants' resonates uncomfortably with 'tale-telling'; the possessive pronoun is exclusionary. 'Research participants' has been used for convenience in the text, yet the people I

have come to regard as friends were far more than ‘participants’; they have been the *raison d’être* of my research. Abstracting myself from these emotionally intense, and sometimes deeply distressing, relationships would not render the account ‘objective’; it would analytically distort the subject matter, namely the obstinate presence of relationships in body part transactions, more concisely the politics of relationships within the organ donation and transplantation process.

We must therefore question the place of the researcher and consider the ability of anthropological inquiry to inform matters of policy and practice in institutional settings. Unlike allegedly objective research which, in its written findings and even its data collection, abstracts the researcher to focus on ‘the subjects of study’, fieldwork practice “is always concerned with relationships,” thus “the autobiography of fieldwork is about [those] lived interactions,” and the embodied knowledge which one’s participation has effected (Okely 1992:2-3). These views resonate also in the current research, which is so fundamentally about relationships. Here, a comment by Rowling (1999:179) is apposite. Research into grief and loss, she argues, requires that the researcher be empathetic, “without being overwhelmed” or “enmeshed.” Rowling suggests “being ‘alongside’ and ‘with’ someone”; a resolution resting upon an interpretation of people as separate and bounded, the implication being that one can conduct such research without being materially affected -- that one walks away with the self intact and unaltered.

The contrary applied in the current situation, where the politics of relationships did as much to obscure as it did to reveal understandings of bodies and persons. I felt compelled to contribute, using anthropologically inspired insights to

present the views of organ donor families and recipients, which I endeavour to do from a perspective other than 'individual rights'.

The reader will find, in effect, two theses which grew symbiotically from the fabric of my research. One thesis is anthropologically motivated; a study of organ donation and transplantation has much to contribute to theoretical development within the discipline. But, as the thesis works both ways, it maintains alongside this a social policy orientation, where I turn the insights anthropology has to offer back upon policies and practices within the transplantation programme. In doing so, I hope to add to the cross-disciplinary literature on organ donation, into which anthropology has begun to venture.

The study sees a manifold need to hark back to the purpose behind Mauss's essay on *The Gift* (1990), which was after all a commentary on the political philosophy guiding welfare provision in Mauss's own contemporary (early twentieth-century) society (Douglas 1990: viii). Mauss's classic text on gift exchange has been directly linked to policy oriented studies of gifts of life within Britain's National Health Service, offering valuable insights on matters of policy and practice which influence the lives of those who give and those who receive (e.g. Titmuss [1970] on blood; Sque and Payne [1994] on organs). Anthropological studies of 'bio-technologies', though not commenting on policy matters, nevertheless demonstrate the possible contributions to a fuller understanding of these phenomena.

Developing a Model for Multi-sited Research on Cross-bodily Transfers of Human Organs

As gifts of life, human organs travel from one body to another; they are physically removed and (re)placed in a transfer which requires extensive, expert, third party biomedical intervention. Interestingly enough, analyses of 'bio-technologies' have mostly focused on one party (e.g. Franklin 1997; Konrad 1999; Titmuss 1970), or they have subscribed to a dyadic model of relationships (Strathern 1997). In doing so the commentators abide by the 'de-relationing' ideology that permeates the subject matter. This study extends the focus to draw in those third party relationships that are insisted upon in the transplant programme.

The politics of relationships permeated every aspect of the current research, including endeavours to recruit participants. Within anthropology a persistent myth circulates that we arrive at our research location, find a place to stay, and 'start networking', to employ contemporary phraseology. The actualities of my own entry into the field could not have been more different. Organ recipients form a tiny minority of the UK population; the occurrence of brain stem death is even less frequent. At the same time, donor families and organ recipients are not 'distinct and marginalised groups'; they are located within Britain's dominant and wider society. The only physical location where 'clusters' form is hospital units; here, legislation and ethical codes entwine, protecting first the privacy of patients and their families and second their well-being if approached to take part in research.⁷ Relatives are not patients but do fall under the rubric of 'healthy volunteers'. General methods of

⁷ For brief history of medical research ethics committees see Alberti (1995:639-640); for national guidelines see Dept. of Health (1991); for critique of variegated practices see Kent (1999).

networking were seriously curtailed while introduction to the politics of relationships in health care contexts was proportionately increased.

Fifteen months were spent in negotiations with hospital units and Research Ethics Committees (RECs) in Scotland, for access to the families of deceased people who did or did not become organ donors, as well as to potential and actual organ recipients. One application was successful, giving access to organ recipients only. Three were unsuccessful, for two broad reasons. First, hospital unit staff and/or REC members were deeply concerned about my lack of experience in dealing with seriously ill or bereaved people; concern was not alleviated by my participation in a bereavement counselling course. The second reason for unsuccessful applications can be located in a lack of fit between anthropological research and biomedical research, exacerbated by the research application process (Wilson 1997; Wilson 1998; Appendices 7 and 8). Disguising processual, flexible, qualitative research in a structure of quantitative methodology is one possible solution, though it de-emphasises the very strong benefits of the former approach. Concurrently, RECs remained unconvinced that my work met the criteria by which it was to be judged -- to benefit particular patients or contribute to medical knowledge -- because of a prevailing view that my research would be intrusive, that it would not be beneficial for bereaved families to talk about the person who had died. Ironically, social isolation is more often the cause of emotional or psychological ill health for bereaved people (McLaren 1998:275-290, esp p279).

Where research involves those cloaked by the protective mantle of medical ethics, we must inquire into precisely when 'research' can be said to have started.

Health care professionals/REC members held that research began when and if REC applications were approved. Yet negotiations required numerous conversations with hospital staff in different specialisations and at several levels of hospital administration and clinical practice, affording excellent opportunity to contemplate the influence of taken-for-granted notions in the formulation and execution of health care policies and practices. Additionally, twenty formally recognised one hour 'interviews' were arranged with nursing staff, physicians, surgeons and other professionals; numbers were biased towards transplantation, where access to staff was more readily negotiable. General information from both forms of discussion is employed here as research data, with every effort to maintain the anonymity of contributors.

Networking with Donor Families and Organ Recipients

Other avenues were required to recruit those most directly involved in giving and receiving the gift of life. A co-ordinator in Scotland's transplant programme had informed me of the British Organ Donor Society (BODY) which holds an annual Convention each year in Cambridge. Delegates include organ recipients and families, donor families, and health care professionals predominantly from nursing. Attendance at the 1997 Convention introduced me to the Transplant Support Network (TSN). Both organisations have been invaluable in facilitating contact with donor families and organ recipients throughout Britain.

Twenty open-ended, face to face conversations, two-three hours in length, were conducted with donor families and organ recipients. Numerous telephone

conversations and exchanges of letters, particularly with two donor families, have been an invaluable source of qualitative data.

During 1999, a small-scale survey provided a secondary source of data channelled towards specific aspects of participation in the organ donation and transplantation process. The survey was not conducted to produce representative percentages or any form of randomised, or allegedly objective, results. Rather, I sought to elicit the personal viewpoints of a geographically dispersed range of donor families and recipients on opportunities for their direct communication with each other, a fraught issue, as I discovered. Questionnaires were distributed to donor families via BODY, the ~~Midlands Donor Family Support Group~~ ^{Network} and the co-ordinators at Freeman Hospital in Newcastle. Organ recipients were invited to take part via the Transplant Support Network's newsletter. Basic collated data and sample questionnaires are reproduced in Appendices 1-5; illuminating comments offered by donor family members or organ recipients are incorporated into the text. TSN Newsletter published an edited version of the research findings (TSN, No. 13, 1999), reproduced as Appendix 6.

Research has drawn on official promotional materials and articles in the general media happened upon by chance, thus reflecting the sort of information which is accessible to the public and which may form the topic of discussion with friends and family, at work, at home, on the bus, or wherever people chat about events in the news. Such materials provided useful data by which to illuminate and dissect aspects of the public performance of organ donation. Three leaflets produced by the Department of Health feature with some prominence; these are reproduced as Plates

1-6 at the end of Part One, to facilitate the reader's own interpretation of their implicit and explicit messages.

Summary

This research considers how organs circulate in gift-of-life transactions, and their impact on everyone involved, paying particular attention to the visibility of organ donors and their families. Donor families can feel that they and their deceased relative are erased from the public performance of organ donation and transplantation.

The initial research project envisaged direct observation of interactions with and around the bodies of organ donors, and organ recipients, to support and query data collected in interviews. Achieving adequate contextualisation presented quite a challenge, not least because the management of organ donation and transplantation, as aspects of our health care service, features significant discontinuities, described in the Introduction to Part Two, which tend to fragment the perspectives of all those involved.

In any event, no access was permitted to hospital units for the purpose of direct observation. The general picture I offer has been constructed from the individual perspectives of all research participants. Despite the partiality of my research focus and the disparate degrees of access to donor families, recipients and health care professionals, I do want to emphasise a roundedness to my own work, which can be missing elsewhere when research parameters do not encompass the wider cycle of exchange transactions involved in giving and receiving human organs. I now outline the presentation of my research in the structure of this thesis.

Part One elucidates dominant popular and academic perspectives on Britain's transplantation programme. Chapter One addresses scholarly discourses which underpin the public performance of organ donation and transplantation as 'the heroics of saving lives' and 'the moral worth of giving'; analysis of the imagery presented in histories of the development of transplantation activity is followed by an overview of academia's defence of altruism, particularly in its articulation with health care provision. Chapter Two engages anthropological and health care scholarship which treats the matter of gift exchange. An alternative perspective is offered on the 'Western person'; the variegated connective capabilities of human tissue and organs are considered, and human organs are proposed as 'a kind of property' with dispersed ownership in other bodies.

Part Two takes as its overarching theme the partiality and positionality of knowledges of the body. The process of becoming an organ donor or organ recipient is viewed as unfamiliar territory where the bodies of donors and recipients are processed in an administrative/clinical system, landscapes being mapped by biomedicine. Certain events or issues marked on those bodies seem to provide signposts for donor families and recipients as they journey through these confusing, frightening realms.

In the Introduction to Part Two, the personal backgrounds of donor families and recipients are presented. The realms of the donor and recipient are described in terms of discontinuities encountered by research participants. The role of donor co-ordinators is briefly outlined.

Chapter Three unsettles the representation of organs as gifts by considering their role as 'resources' in a health care context increasingly permeated by market economics. Becoming an organ donor is traced as an anonymising process contested by shifting subjectivities, followed by theoretical explication of this oscillating process. The chapter concludes by reviewing proposed methods to increase the supply of organs for transplantation, contextualising the vigour of public campaigns for deceased donation.

As the crux of this thesis, Chapter Four takes as its central focus the erosion of voluntarism and the erasure of (donor/donor family) persons from the public performance of organ donation and transplantation. The process of becoming a donor family is reviewed in some detail. Attitudes towards bereaved people, which amplify their sense of erasure, are then discussed. The chapter concludes by tracing the gradual erosion of voluntarism as first, 'card-carrying' organ donors then second, donor families move through the process of organ donation. Fundamentally, there is no conclusion to this process.

Chapter Five carries forward the process of becoming an organ recipient. Themes of guilt and gratitude emerge. Health care professionals may seek to keep the 'narratives of life and death' hidden to protect the well-being of recipients and donor families. Various methods are used to deflect the attention of each away from the other. Such strategies serve to submerge, if not to sever, the connectivity of recipients and donor families.

Part Three amplifies the tension between autonomy and connectivity. The clinical practice of organ transplantation articulates with the nation-state in a

discourse of individual rights and consumer values; concurrently, giving and receiving human organs generates the 'dispersed enactment of self' (Jean-Klein 2000:5) through the connectivity of donor families and organ recipients, where enactment encompasses 'the present absence' of the deceased donor (cf. Battaglia 1990:196).

The Conclusion revisits the central argument of this thesis, that the transacting of human organs is a moral economy, ill-served by its public performance as voluntary, anonymous and altruistic.

PART ONE HUMAN ORGANS AS GIFTS: HEGEMONIC DISCOURSES AND THEORIES OF EXCHANGE

Chapter One

The Moral Worth Of Giving And The Heroics Of Saving Lives: Quotidian Perspectives On The Transplantation Programme

When it comes to matters of life and death anthropology understands that 'the moment of death' is culturally variable, as are opinions about what should, or should not, be done to dead bodies (e.g. Bloch & Parry 1982; Metcalf & Huntington 1991). In Britain, these are issues over which biomedical science has considerable, though not total, influence. Historically, in Britain, deaths at any age were frequent occurrences, life expectancy was comparatively low, and the majority of people died at home in the presence of family and friends (Gittings 1984:6-7).

Today, most deaths occur in professional care facilities, among the very old (Sidell 1993:151). Death has become a wholly negative event, excepting instances where it brings release from painful and prolonged dying. Whatever the historical processes proposed for death's displacement beyond our social margins (compare for example Gittings [1984] and Houlbrooke [1989]), improvements in health care over the course of the twentieth-century have had an impact, though disproportionate emphasis may be given to curative rather than preventive developments (Coleman et al. 1993:2 citing McKeown 1979). Medical and surgical treatments, as well as broader improvements in many areas of our daily environment, have brought death under control to an unprecedented degree. For those whose lives are threatened, biomedical

science can and does offer dramatic forms of intervention, hence their continued high public profile.

Taking the internal organs -- the heart, lungs, liver and kidneys -- from a body which has been declared dead, and transplanting them into other bodies to ward off their death is an example of such intervention (O'Neill 1996:5-6). Transplant surgeons today may not achieve the international status of Christiaan Barnard, who carried out the first heart transplant. In fact, one surgeon I interviewed remarked that there was no glamour left in the specialisation, which was suffering because it lacked the 'bazazz' to attract new surgeons. Yet among their patients, surgeons may still be treated with a degree of religious awe. As one recipient remarked to me, "my wife thinks Mr X walks on water." Transplant surgery still resonates with "the heroics of saving lives" (Lock 1996b:164; cf. Machado 1998:2-3). It should not be forgotten, though it often is, that the success of transplantation depends upon failure in another area of health care (cf. Lock 1996a:219). Without the phenomenon of brain stem death, we can safely surmise that the transplantation programme today would have looked very different indeed.

This chapter demonstrates how historical accounts of transplantation present the development of this clinical enterprise as a heroic journey. It goes on to look at the redefinition of death as brain stem death, and controversy over the nature of its interconnection with the development of transplantation. Current promotional literature for organ donation is then reviewed. The current ethnography lends support to Lock's view of the situation in the USA, that "the desire to save lives has apparently overridden most concerns about the remaking of death" (Lock

1996b:164). As the title of this chapter indicates, “the moral worth of giving to needy others coupled with the heroics of saving lives” (Lock 1996b:164) renders organ donation a highly commendable action. Machado (1998:5) has suggested the hero is more likely to be “modern medicine” than the organ donor (cf. Fox and Swazey 1974). Nevertheless, organ donation is promoted and widely understood as an act of altruism; a selection of materials illustrate subtle and not so subtle metaphorical representations of organ donation as an altruistic gift. By way of illustrating the tenacity of the notion of altruism, the chapter ends with a review of academic literature produced in its defence as a guiding principle of Britain’s welfare system. Particular reference will be made to the National Health Service, within which organ transplantation is located. My own arguments cannot ignore the strength of altruism’s defence, carried as it is into health care scholarship on organ donation, to which I turn in Chapter 2.

I The Development of Organ Transplantation

In his Introduction to a recent medical textbook, the editor noted that “the history of transplantation is by itself an introduction to modern clinical advance” (Hakim 1997:1). Where histories of organ transplantation are recounted, a sense of pioneering heroism and “trailblazing” is often apparent (Kahan 1996:129; cf. Machado 1998:1-2). The researcher witnessed one such presentation at a public meeting where ‘a very eminent and pioneering surgeon’, as he was introduced to the audience, regaled us with a number of ‘ripping yarns’ about the early days of transplantation, as when the speaker had conducted ‘retrieval operations’ on donors in ambulances as they whizzed towards the potential recipient’s transplant unit. Anecdotes of this kind can be used to add spice to the more ‘matter of fact’ tone of textbooks, and consciously or unconsciously take the sting out of early failures. By way of marking a significant step in the treatment of kidney disease, one textbook (Hakim 1997:6) refers to the surgeon who made an early dialysis machine from “sausage casing and tomato cans.” His patients nevertheless died. Of these efforts he was heard to remark “it was a good thing the boss was away!”

Histories of transplantation may locate contemporary practices within a very long tradition. Teeth, we learn, were transplanted in many countries of the ancient world (Peer 1995:25-29). Skin grafting was recorded in a Sanskrit text of “at least the second or third century BC” (BODY 1991). The extraordinary story of Cosmas and Damian transplanting a human leg has been recorded in numerous works of art from the Middle Ages (see prints in Barkan 1996:229-35). Barkan (1996) cautions against drawing analogies between contemporary transplantation practices and these ancient,

or not so ancient, examples. Analogies are drawn, nevertheless, though the beginnings of organ transplantation 'as we know it today' tend to be given their origins in the eighteenth or nineteenth century at the earliest. Bone grafting for example was successfully carried out by William MacEwen in Glasgow in 1881 (BODY 1991:1).

Having established clinical transplantation's historical credentials, stories tracing its development proceed genealogically, as a linear progression from one 'breakthrough' to another. First 'successful' attempts are marked by date, place and surgeon, though the measure of success has altered over the years. The first 'successful' kidney transplant was carried out in Boston in 1954 by Thomas Starzl; the patient lived for eight days. Today, success is measured in terms of years -- for example 75% survival at one year. Failures are not forgotten, but are presented as laying valuable foundations for future research or as courageous pioneering of the sort discussed by Fox and Swazey (1974) in the book aptly titled *The Courage to Fail*.

Other significant landmarks in the advance of transplantation are noted -- the discovery of 'rejection' where the host body's immune system acts to dispel 'alien' tissue; work on immunosuppressant drugs to counter this effect; the importance of tissue typing; the release of Cyclosporin, the most powerful anti-rejection drug, in the mid 1980s. Thereafter, transplantation of all the major solid organs multiplied and spread world-wide. From a handful of liver transplant operations in 1983, over 6,000 were being performed per year by 1992 (New et al. 1994:14).

Yet the most extraordinary development in transplantation happened outwith the transplant programme. Kidneys could be transplanted from living donors since they are paired organs and otherwise healthy people can survive adequately with one.

The transplantation of other major solid organs developed through using the bodies of the dead.

Brain Stem Death

Until comparatively recently, permanent cessation of heartbeat and breathing were the standard signs of death, “followed almost immediately by death of the brain” (Lamb 1985:72). Technological advances in biomedicine now mean that, when people are rushed to hospital with suspected traumatic head injuries, or have otherwise collapsed, experiencing temporary cardiac and respiratory arrest, they are placed on ‘life support’ as part of the effort to save their life. This includes a ventilator which takes over their breathing, augmented by drips which control the body’s chemical balance, and catheters for urinary excretion. However, if damage to the brain is extreme, brain stem death occurs. The heart continues to beat for a while but it will cease spontaneously within days even under ventilation (Dept. of Health 1998:8). Because of the availability of life support technology, and as long as the heart continues to beat, the body’s tissues and organs remain living and available for transplantation.

The earliest reports of the condition which came to be termed brain stem death appeared in the late 1950s. One described six patients on life support systems, where there was no evidence of blood flow within the cranium. The patients were declared dead after cessation of heartbeat, which occurred variably within a period spanning twenty-six days (Lofstedt and von Reis 1956). Three years later, French neurologists described the condition of such patients as *coma dépassé* (Mollaret and Goulon

1959). The term 'brain death' appeared in 1965, in a report about a kidney removed for transplantation from "a heart-beating, seemingly brain-dead donor" (Alexandre 1991, cited in Powner et al. 1996:1220).

Brain An early step to develop formalised diagnostic criteria for brain stem death was taken by the Ad Hoc Committee of Harvard Medical School (JAMA 1968). Britain's medical establishment followed the USA somewhat more sedately, with statements on brain stem death from the Conference of the Medical Royal Colleges and Faculties of the UK in 1976. The then Department of Health and Social Security responded in 1979 (revised 1983 and 1998) with the production of guidelines for diagnosis, and the use of the deceased patient's organs for transplantation. Lock finds it "significant" that Harvard's Ad Hoc Committee produced its criteria "shortly after the world's first heart transplant" (Lock 1996a:215). She argues that "reaching a medical consensus ... was clearly linked from the outset to a demand for human organs" by noting that the Committee's second main reason for developing the criteria was because "obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation," the first reason being to reduce the emotional and financial burdens on families and hospitals (Lock 1996a:215-6). In a meticulous review of the Harvard Ad Hoc Committee's proceedings, Giacomini (1997) offers a strong argument for a direct causal link between the needs of the USA's transplant programme and the establishment of brain stem death criteria. The causal link is, by now, perhaps academic. If all transplant activity was to cease, this would not mean that the incidences of brain stem death would also cease. Yet the link is irrevocably

present and has led over the last few decades to substantial publicity encouraging people to think about becoming organ donors in the event of their deaths.

Promoting Organ Donation

In this section, I briefly outline how the promotion of organ donation has developed and how information is disseminated, before turning to examine the presence of gift metaphors within promotional, popular, and academic materials.

Donor Cards

Approximately 10 million organ donor cards are circulated every year (New et al. 1994:48). Donor cards appeared as a private initiative in 1971, when they involved the kidneys only, but they were soon taken up by the then Department of Health and Social Security (DHSS). In 1981, the donor card became ‘multi-organ’ with the inclusion of the heart, liver, pancreas and eyes; the lungs were added in 1985 and the eyes were changed to the corneas in 1988 (UKTSSA correspondence).

The Donor Register

Launched in 1994 by the then Parliamentary Under Secretary of State for Health, the Register is currently maintained by the United Kingdom Transplant Support Service Authority (UKTSSA). This centralised database allows health care professionals working in transplantation to check whether a suitable deceased patient had registered the wish to become a donor.⁸ Registration is facilitated in a number of ways. The

⁸ The Authority also keeps a record of all potential recipients, and allocates organs through a series of waiting lists.

decision can be indicated on an application form for a driving licence, or when registering with a new general practitioner. In both of these cases, the information is directly transferred to UKTSSA. Registration forms are also sent out by the UK Passport Agency, but these have to be returned by individuals themselves, as do the registration forms which can be found in public places such as libraries. Registration forms are often part of an information leaflet, which also has a detachable donor card.

Human Organs and the Metaphor of the Gift

The term 'gift of life' is widely understood to refer to organs for transplantation, so much so that the need for many other forms of tissue tends to be overshadowed, according to an educational leaflet about Britain's Tissue Banks (British Association of Tissue Banks 1997). Women whose ova are extracted and used in fertility treatments consider themselves to be giving 'gifts of life' (Konrad 1999:645). During the present research, the terms 'gift' and 'gift of life' were frequently encountered. In popular media, the effect was often dramatic. On 5th May 1997, the *Edinburgh Evening News* carried a front page story about a young man who had committed suicide; his father spoke of how the young man had "left the gift of life for others," as his kidneys and liver had been removed for transplantation -- redeeming even the act of suicide. Similarly, the *Big Issue in Scotland* (1997:6) carried an article headed 'the long wait for the gift of life'. An educational pack for health care professionals, prepared by the Scottish Transplant Co-ordinators, was titled '*The Gift of Life*' (personal communication), the title also given to three information booklets produced by the British Organ Donor Society (BODY). References to organs as 'gifts'

appeared in research questionnaires returned to me by recipients and donor families, in academic writings (e.g. Sque and Payne 1994), and books by recipients (Hatton 1996; Sylvia 1997). The Department of Health promotional leaflet from 1996 (Plates 3-4) carries the phrases 'gift of life' and 'a gift without price'; the word 'gift' appears twice in a recipient's quote, and a gift appears, literally, being carried by a man in one of the leaflet's several photographs.

What is it, then, about allowing one's organs to be removed after death that renders them so obviously as 'gifts'? Two publicly promoted aspects are significant -- organs are to be given first, voluntarily and second, altruistically, a view encountered in various research contexts where the status of the organ as a gift seemed in no doubt. A third quality, of anonymity, rather reinforces the other two.

On their voluntarism, certainly in Britain, gifts are assumed to be given as a matter of choice (Carrier 1995; cf. Strathern 1997). In promotional leaflets designed to encourage people to carry donor cards terms such as 'option', 'wish to donate', 'request to be a donor', and 'when you decide' are featured. Arbitrary removal of organs from the dead is not institutionalised in British law, though health care professionals have more authority to remove organs without consultation than is generally known (see Chapter 4). Nevertheless, people spoke to me about how they, or their relatives or friends, had *chosen* to carry donor cards. Choice extends into which organs one prefers to donate.

Altruism is broadly understood as giving with no expectation of return. In her Foreword to *The Gift*, Douglas (1990: vii) describes the "unrequited surrender of resources" as 'charity', widely perceived in Britain as generosity, and represented in

one promotional leaflet through the use of a heart motif (Dept. of Health 1998, Plates 5-6), a symbol of loving and giving. Several hearts appear on the leaflet, increasing in size until the largest extends off the page. One might surmise that donor anonymity decreases the impact of the gift's altruism. Promotional leaflets emphasise that donor identities will not be revealed to recipients, though donor families may be told how organs were used. If recipients do not know who gave this gift, no return can be made; potential donors are presumably happy with this arrangement. Yet the perception of organ donation as a generous act is rather amplified by the giver's concern for unknown people. In casual conversations with members of the public and academic colleagues, as well as more formal discussions with health care professionals, potential recipients, and donor families, organ donation was explicitly linked with the morally valued ideal of saving lives (cf. Lock 1996b:164). Studies of donor families in the USA found organ donation regarded as "the highest form of charity" (Bartucci and Seller 1986:104), in a context we must remember where blood is bought and sold. Donor families in the present study similarly emphasised the generosity, the concern for others, the selflessness, of their loved one, who took the time to think about his or her own death, and decide to become an organ donor. Their moral worth was regarded as having been *demonstrated by* the act of donation, rather than achieved by it. In other words, the donor was already an exemplary person, in the eyes of his or her family.

To re-iterate, then, organ donation is promoted and understood as the voluntary, anonymous and 'unrequited surrender of resources'. Its quality as a gift is strongly reinforced in promotional materials, popular media and academic literature.

The model of voluntary, benevolent gestures towards others with no expectation of a direct return ('altruism') is implicitly assumed and explicitly defended in academia, not least in relation to policies for welfare provision generally (e.g. Pemberton 1990; cf. Schrifft 1997:18-20), health care particularly (e.g. Page 1996) and tissue and organ donation specifically (e.g. Titmuss 1970), as shall be seen in the next chapter. It will be useful, therefore, to examine here the tenacious nature of both the notion of altruism and its academic defence.

II Scholarly Discourses on Altruism

The term 'altruism' was originally offered by Auguste Comte to describe "a principle of moral conduct based on regard for others" (Ingold 1986:277, citing Hawthorn 1976:78) in contrast to egoism, that is selfishness, as the motivating force of human behaviour. Since then, a very substantial literature has accumulated, on altruism and its wider theoretical context of gift exchange, of which the present study can give but a glimpse. To paraphrase Parry's (1986) remark on Mauss's (1990) essay, it is not my intention to argue that there is no such thing as altruism; my interest lies in examining why people think there should be altruism, and the implications of this for organ donor families and organ recipients. The following summary is therefore a review of how the historical development of altruism is reported, and a critical appraisal of what has been and continues to be viewed as altruism within Britain's welfare system.

Contemporary Discourses on Altruism

The 'theme of the gift' has been described as a focal point at the intersection of intra- and inter-disciplinary discussions of deconstruction, gender, ethics, philosophy, anthropology and economics (Schrift 1997:3). Within the literature, there is general understanding that the giving of gifts implicates of necessity some form of relationship between the giver and receiver. Forms of relating range from the intensely personal relations of love wherein "the gift finds perhaps its most perfect expression" (Schrift 1997:7; cf. Emerson same volume), to a generalised sociality which permits of "state-sponsored gift giving" (Schrift 1997:16).

In his presentation of altruism as opposed to egoism, Comte made no distinction between selfishness and self-interest (Page 1996:34). Subsequent studies have considered whether altruism may include self-interest; arguing that altruistic behaviour should have no expectation of reward "from the object of the altruistic behaviour" (Cohen 1972:41) or more broadly "from external sources" (Macaulay and Berkowitz 1970:3). Others have concluded that some benefit to oneself, even a sense of personal pleasure, is acceptable (Leeds 1963:230-31), provided it is not the primary intent (Sorrentino and Rushton 1981:427).

Attention has been given to agency, placing altruistic behaviour beyond the imperatives of duty or obligation (Leeds 1963:230-31), in favour of spontaneous empathetic (Cohen 1972) or sympathetic (Collard 1978) responses to the needs of others. Attempts have been made to explain altruistic behaviour in humans through genetic determinants (e.g. Wilson 1975) derived from studies of non-human animals which provided behavioural theories (e.g. group selection [Wynn-Edwards 1962], kin selection [Hamilton 1964] and reciprocal altruism [Trivers 1971]). Philosophers have utilised such studies to account for human social life (e.g. Midgley 1994). In economics, mathematical theories have been applied to the same end (e.g. Stark 1995). Collard argued for a 'rational altruism' in opposition to the rational, self-interest propounded by contemporary economic textbooks (1978:3). Yet Western economists have also been criticised for their inability to comprehend systems of exchange beyond that of the Western economic market (Gregory 1983). A dichotomous model of 'gift societies' opposed to 'commodity societies' pervades this latter discourse, with frequent reference to Mauss's (1990) essay on gift exchange.

Historical Accounts of Altruism

I develop this section with reference to ‘state-sponsored gift giving’ (see above). In Britain the origins of ‘welfare altruism’ have been traced to the teachings of the early Christian church, where an “active concern for others rather than self” was seen as a Christian duty (Page 1996:17; cf. Tierney 1959:46), though such acts also included an element of self-interest in as far as they were conducted in the hope of attaining salvation (Page 1996:17-18). During the sixteenth century, the doctrine of salvation through the performance of charitable works was undermined by the teachings of Luther and Calvin, the latter believing that salvation would come to those who worked hard, and actively sought to bring the influence of religious faith into every aspect of life (Reardon 1981:111). Aspiring entrepreneurs and capitalists favoured Calvin’s teachings, so that economic success came to be seen as a sign of salvation (Giddens 1976:5) -- this is the doctrine of predestination. Thus, Calvinism simultaneously “helped to secure the acceptance of an ‘unfettered’ economic individualism within society” (Page 1996:20; cf. Weber 1958) and, during the seventeenth century, provoked an upsurge of charitable works particularly in the area of education and training, reflecting the doctrine that wealth should not be spent in a self-indulgent fashion (Page 1996:19).

As a “*demonstration* of faith and a prospective state of grace” charitable works were stripped of self-interest; self-interest being understood as the less noble Catholic doctrine of achieving salvation through the *execution* of good works (Page 1996:21-22 emphasis added). By the mid-seventeenth century, “charitable activity had

become an established feature of English society” (1996:21-22), activity represented as altruistic, that is nothing expected or received in return. While comparisons between historical and contemporary situations should be treated with caution, one can see here a strong resemblance to organ donation, where the moral worth of donors is shown by, rather than gained by, the act of donation. A broad difference resides in the secular character of contemporary Britain, where acts of altruism do not necessarily spring from religious convictions.

Political developments in the eighteenth century restore the comparison, as ‘the state’ begins to adopt a welfare role influenced by scientific, utilitarian principles (Page 1996:23-25). Collective philanthropic organisations became widespread; their activities, considered to be a civic duty, were based on humanitarian principles and supported by the state (Page 1996:22). Into the nineteenth century, the state’s scientific approach increased, with ‘poor relief’ based on the ‘factual’ assessment of individual cases (Page 1996:24-25). Private philanthropic organisations developed in a similar fashion, yet imbued their work with a “Christian concern for individual suffering” (Prochaska 1988:43). In the wake of threats to British economic and military supremacy, the latter half of the 19th century witnessed a strong state-sponsored drive for national efficiency in a society increasingly individualistic in orientation. Ethical liberal organisations such as the Fabian Society criticised an economic system which encouraged competitiveness and personal acquisition, yet excessive state intervention was not regarded favourably since it would tend to undermine self-reliance and independence (Page 1996:27-8). “Ethical liberals idealised the market relations ... of early capitalism (where) responsible citizens ... freely

contracted with each other *for their mutual advantage*” (Bellamy 1992:3, emphasis added). Stronger views on altruism were expressed. Peripheral to the Fabian Society, Clifford argued that only socialism could produce unselfishness (Page 1996:41). J.S. Mill, though a strong proponent of individualism, with its prioritisation of self before others, held that altruistic behaviour was indicative of ‘civilisation’ (Page 1996:35). Paradoxically, autonomy and paternalism went hand in hand (Hockey and James 1993).

The foregoing suggests that the need for altruistic behaviour developed in tandem with economic individualism. Indeed, it was during the 19th century that the debate arose between selfishness and selflessness as the basis of human nature. Comte held that acts not directed towards the benefit of others were “inherently selfish” (Page 1996:34), while Spencer argued that an extension of familial altruism into society at large was acceptable to promote social intercourse, but benevolence should not be directed to “good-for-nothings” (Collard 1978:45). Segregating those who deserved help from those who took advantage of assistance has a long history. Page notes a tendency of the early Christian Church to distinguish between the ‘deserving’ and the ‘undeserving’ poor, though the small scale nature of feudal society afforded limited opportunities for abuse of the relief system (Page 1996:17-18). Similarly, the nineteenth century saw perhaps the strongest response to possible abuse of state sponsored welfare in compulsory workhouses and financial assistance below the lowest possible wage level (Page 1996:25-26). Reports of people who misuse the welfare system continue to feature prominently in contemporary media today. One might assume that organ transplantation would be free of any such moral evaluations.

As we shall see, while potential recipients demonstrably need organs -- the alternative being death -- the scarcity of organs does render the assessment of suitable recipients morally necessary, if problematic.

In contrast with individualised analyses of poverty, by the early twentieth-century it was increasingly argued that poverty had structural, rather than personal, causes, and that the State was obligated to provide adequate assistance (Page 1996:28-29). Doubt has been expressed about the humanitarian motives of these reforms, not necessarily supported by the people -- especially those who came under their control -- since they were generally aimed at maintaining, rather than eradicating, existing social and economic relations (Page 1996:53-4). However, the Second World War does appear to have impacted on rigid class divisiveness, generating a "willingness ... to offer help to strangers without expectation of either reciprocity or reward" (Page 1996:82), and giving rise to the view that "purposeful state welfare activity could ... provide the foundations for the creation of a fairer post-war society" (1996:60). The result was the development of the Welfare State.

Assessments of Welfare Altruism Today

The continuing success of Britain's welfare system has been attributed to "a more selfless spirit ... a greater public appetite for pooling risks rather than entering into highly individualistic arrangements" (Page 1996:83). Given the resurgence of "individualism, self-help and competition" in the latter part of the twentieth-century however, Page suggests future measures should "appeal to self-interest as well as selflessness" (1996:146-7) though he concludes his analysis of 'welfare altruism' with

a rallying cry in its defence (Page 1996:150). Holman (1993:57) similarly evokes “mutual obligations towards others, stemming from the acceptance of common kinship” as a determining factor in maintenance of the welfare state. Hennessy is of the opinion that the National Health Service “is the nearest Britain has ever come to institutionalising altruism” (1992:132). Within the Health Service, R.M. Titmuss, an influential writer on liberal social policy, regarded the national blood transfusion system as exemplary of “sentiments of altruism, reciprocity and social duty ... explicit and identifiable in ... all social groups and classes” (1970:225).

In this brief review, the term ‘altruism’ has been applied to behaviour which does and does not include self-interest, motivated by (variously or simultaneously) love, sympathy, empathy, Christian duty, civic responsibility and mutual obligations, conducted by individuals who esteem independence yet create dependence by refusing to permit reciprocity. Despite the assumption of autonomy and voluntarism in altruistic behaviour, all the developments discussed above feature an external agency responsible for provoking, or encouraging, or fostering that behaviour. For the early Christians it was God; by the Age of Reason, the State was beginning to assume the role; for some, that state had to be socialist; liberal utilitarians bowed to contractarian ethics; Titmuss accorded such influence to the nation’s blood transfusion service; a century apart, Spencer and Holman evoked kinship connections. In other words, action does not arise spontaneously from autonomous free choice. It must be elicited. Finally, though kinship connections were evoked to foster a more general sociality, none of the behaviours described as altruistic envisaged the creation or maintenance of particular relationships.

Summary

This chapter has introduced popular and academic perspectives on organ donation, paying particular attention to the presence of the gift metaphor, demonstrated in appraisals of organ donation as the generous consideration of others, a gift freely given with no expectation of personal benefit. Specifically, since the donor is deceased as a condition of the transaction, the possibility of a relationship between the giver and the receiver is excluded.

It has become apparent through the historical review that the notion of altruism is idealised, applied to gestures displaying a wide range of motives which may or may not admit of self-interest; those arising from a sense of duty or obligation towards others may or may not be excluded. The majority of analyses prioritise the point of view of the giver, with limited attention directed to the effects of such activities upon receivers, beyond the assumption that altruism as ‘generalised generosity towards strangers’ is good for everyone, at least in the context of the welfare state. Here, according to Titmuss (1970), altruism is exemplified by those who freely give blood. The altruism associated with welfare activities is predicated on the assumption that it is given by an autonomous, independent individual, yet external agencies have, simultaneously, been accorded the ability to ‘foster’ altruism in the general public.

Throughout this thesis, we shall be considering the location of agency with regard to giving the gift of life, while also paying close attention to the interconnections between human organs and the relationships animated by their cross-

bodily transaction. In the next chapter, I review theoretical analyses of gift exchange in general and involving the use of human tissue and organs in particular. A cautionary note is introduced since I shall argue that 'the gift of life' is a homogenised term, inappropriately applied to a range of bodily substances given and received in diverse situations. Consequently, we are required to adjust the analytical framework to render it theoretically relevant to the 'gift' in question.

Chapter Two

Theorising Gifts Of Life: Applying Anthropological Theory To Human Tissue And Organ Transactions

Within both the discipline of social anthropology and the context of everyday life in Britain, the terms 'gift' and 'gift exchange' have particular but not necessarily similar connotations. This situation has in turn implications for the manner in which anthropological analyses are applied to the transacting⁹ of human tissue and organs. To prepare the foundations for my own analysis of solid organ transactions, this chapter reviews a number of ethnographic and theoretical studies, both anthropological and non-anthropological. Some have treated exchange systems in general; others offer a more finely tuned focus on bio-technologies.

Broadly speaking, the studies share a common ancestry founded on a now classic text by Marcel Mauss. A substantial part of *The Gift*, first published in French in 1923-24 (Schrift 1997:323), drew on a small number of reports of exchange economies in Melanesia. Mauss (1990) concluded that the morality governing so-called 'gift economies' could readily be adopted by people in Western 'commodity economies'. Over half a century later, one of anthropology's most influential scholars of Melanesia, Marilyn Strathern, could draw on two generations of Melanesian ethnographies to produce her authoritative monograph, *The Gender of the Gift* (1988). In the view of Strathern, the kinds of persons implicated in Melanesian forms of gift exchange are irreconcilably different from persons in Western settings. Although the central arguments presented by Mauss (1990) and Strathern (1988) are

⁹ From this point, I have tended to favour 'transacting' which emphasises the prominent participation of others in this cross-bodily transfer of tissue and organs. 'Donation' will be used when attention is focused on those from whom the tissue or organs are actually removed.

themselves apparently irreconcilable, this chapter seeks to demonstrate a considerable degree of compatibility in their application to the transacting of human tissue and organs.

Viewed within the frame of the current research, Mauss's theory still holds relevance for contemporary studies of exchange economies, though it is his methodology to which I draw special attention in this chapter. Mauss argued that to understand exchange practices in any context one must also understand how people, objects, and the links between them are perceived. His methodological approach has important implications for comparative studies of human tissue and organ transactions.

In relation to my own study of solid organ transactions, three points require emphasis. First, analyses of bio-technologies conducted within or outwith the discipline of anthropology cannot assume any homogeneity to human tissue and organs, either as 'gifts' or as 'biological material'. To do either privileges certain progressions of argument, leaving other important features unchallenged. Using ethnographically and theoretically based analyses of various forms of tissue and organ transaction, I suggest that each kind of 'bio-gift' requires an analytical framework specific to the conditions of its production and transaction.

The second point to be emphasised is that analyses of human tissue and organ transactions have tended to focus on one or at most two parties to the transaction whereas, I argue, an adequate understanding requires that we examine the effects of the wider transacting process on everyone involved. This broader methodological approach reveals that the transacting of human tissue and organs consists of what

might be viewed as a series of dyadic exchanges, each of which offers different interpretative possibilities, lay and academic, as regards the kind of object and the kind of person implicated in the exchange.

This brings me to my third and last point -- the category of 'the person'. Particularly relevant here is the tendency in anthropology to juxtapose 'Western' systems of exchange with 'other' economies, carrying implications for anthropological notions of personhood. While it is understood within anthropology that analyses of exchange practices necessarily require a careful consideration of the form of person implicated in those practices, it is time to remember that the homogenised model of the 'Western person' renders hegemonic discourses rather than ethnographic realities.

The material in Chapter Two has been broadly divided to trace two different approaches to the study of bio-technologies. Section One addresses the work of Strathern (1988, 1997) whose principal concern has been 'other' economies of bodies and persons. She thus foregrounds the kinds of persons implicated in different exchange forms, including human tissue and organ transactions. At this point, I take some time to review interpretations of 'the person' apparent in academic literature, before outlining my own understandings of the terms 'individual' and 'person' as they are manifested in the current research. In Section Two, I turn to Mauss's essay, *The Gift* (1990), which juxtaposed 'other' economies of exchange with Western market economies. Mauss's theory has been applied to studies of bio-technologies within welfare scholarship refracted through socio-culturally specific interpretations of 'gifts' and giving, as Carrier's (1995) research will illustrate. In Section Three, my own operationalisation of Mauss's theory frees it of certain restrictive assumptions;

interweaving my interpretation of 'individuals' and 'persons', I show how Mauss's central argument can be applied to further our understanding of human tissue and organ transactions.

One of the more strategies on which Strathern's work relies is to "draw out a collection of ideas about the nature of social life in Melanesia by pitting these against ideas presented as Western orthodoxy" (1989: 12, emphasis added).¹ Strathern's strategy and justification of 'individual' and 'person' Strathern does not claim her work as he held as orthodox by all Western thinkers. But, the model of the Western person which she operationalises does hold a significant degree of currency within anthropological circles (e.g. Becker 1975; Barth 1989; Morton and Martin 1993) and thus relating to Western culture as discussed in the previous chapter. My work focuses on this orthodoxy of the Western person as the individual as an autonomous, free-willing entity, detached from all other individuals, so that relationships with others are presented as being entered into after the fact of the individual's personhood. It is this orthodoxy that I will now seek to deconstruct.

Using this model of the person, Strathern argues that the value of Western

I Strathern and the (Re)production of Persons

Strathern's work, shaped by her extensive knowledge of the literature on Melanesian exchange forms, illuminates the constitution of bodies and persons in the Melanesian context through 'other' economies of exchange. The process is most extensively elucidated in *The Gender of the Gift* (Strathern 1988). Conveniently, a synopsis of sorts accompanies her stimulating contribution to *The Logic of the Gift* (Schrift ed.1997). Here Strathern applies her theory, shaped by Melanesian ethnographic materials, to the matter of 'bio-technologies' in Western settings.

One of the core strategies on which Strathern's work relies is to "draw out a certain set of ideas about the nature of social life in Melanesia by pitting them against ideas *presented as Western orthodoxy*" (1988:12, emphasis added), namely the separation and juxtaposition of 'individual' and 'society'. Strathern does not claim her ideas to be held as orthodox by all Western thinkers. Still, the model of the Western person which she operationalises does hold a significant degree of currency within anthropological analyses (e.g. Becker 1995; Bloch 1988; Morton and Macintyre 1995) and those relating to welfare altruism, discussed in the previous chapter. My work focuses on this orthodox form of Western person -- that of the individual as an autonomous, free-standing entity, detached from all other individuals, so that relationships with others are presumed to be secondary, "after the fact of the individual's personhood rather than integral to it" (Strathern 1997:298; cf. Strathern 1988).

Using this model of the person, Strathern argues that the value of Western gifts derives from either relationships with specific people which carry "special

connotations of intimacy” or a diffuse relationship to ‘society’ which features “altruism as a source of benign feeling” (Strathern 1997:303). Furthermore, the generative power of exchanges is located, in this metaphysics, in the individual’s own desires and agency. We give and receive because we want/choose to do so (Strathern 1997:306). Twentieth-century Westerners live in a self-advertised consumer culture, dedicated to free choice, where gift-giving is highly personalised; in other words, consumption is about *personalisation* (Strathern 1997:295, my emphasis). Based on her understanding that goods may express personal identity without being gifts and that gifts can make statements about, but do not necessarily make, relationships, Strathern insists that in Western settings -- “*the circulation of gifts does not create distinct kinds of persons*” (Strathern 1997:302, her emphasis). Contrastively, Melanesian gifts are elicited by the potential recipient, where the identity of the giver is carried by the gift, and where that identity is significant to the identity of the recipient (Strathern 1997).

Strathern On ‘Bio-gifts’

Applying this perspective to bio-technologies, Strathern (1997) argues that anonymity and voluntarism are ideologically paramount in organ and tissue donation. In her commentary on assisted conception, Strathern notes that semen or ova may be elicited by a specific person, i.e. a known recipient, but both can proceed anonymously; fertilisation occurs, and an embryo takes on its own identity, whether or not donors and recipients are known to each other. “Donation linking a person to a source of genetic endowment does not necessarily link the person to another person”

(Strathern 1997:300). Extending her argument to the donation of solid organs, organ donors “can give anonymously because human organs are regarded as anonymous: kidneys differ in physical condition rather than social identity” (Strathern 1997:301). At this point Strathern acknowledges that “ties are occasionally established” between donors and recipients (1997:310, note 38), based on Abrahams’s discussions with transplant surgeons (Abrahams 1990).

On voluntarism, Strathern holds that the Western individual, as consumer, may be ‘compelled’ to act, but only “in the desire/drive/need for the individual to act as a free agent,” not through the needs of others (1997:304). While “the Melanesian capacity to receive has to be nurtured in and elicited from a partner, sometimes to the point of coercion, the twentieth-century consumer is depicted as having infinite appetite” (Strathern 1997:306). We can think in terms of consumer choice because “*anything consumed by that person comes from the outside*, whether or not the source is other persons. For generative power lies in the individual person’s own desire for experience” (Strathern 1997:306, her emphasis).

Strathern’s discussion concludes with the most salient contrast between Melanesians and Westerners. Melanesians have one kind of relationship -- interpersonal -- and gift exchange presupposes “two kinds of persons, partners divided by their transaction [and] a partnering of finite identities”; Westerners have one kind of person, and gift exchange presupposes “two kinds of relationships ...interpersonal relations with others and ... relations with society” (Strathern 1997:307). Under these circumstances, “the gift capable of extending a personalised

self into a potentially infinite universe turns the person into a potential recipient of everything" (1997:307).

Re-thinking the Western person

Intensive research with the families of deceased organ donors and the recipients of transplanted organs has led me to question anthropological understandings of 'Western persons', and the extent to which we can be represented as bounded and autonomous units (Bloch 1988:16), 'distinctive wholes' (Geertz 1983:290). Such a representation is seriously curtailed by the fact that one or more parts can literally be removed from one body and placed into other bodies, a bio-technological development which has, by all means, extended our 'capacity to consume' in extraordinary ways.

Yet, as a direct consequence of this very development the current research confronted me with what seemed rather more than "one kind of person" (Strathern 1997:307). The kind of Western person depicted by Strathern (1997) was evident in certain contexts. We glimpsed this person in Chapter One, an individual accorded political autonomy and the right to make choices about organ donation. However, as I listened to people describing the effects of their participation in the transacting of human organs, kinds of connections emerged entirely integral to their perceptions of personhood, reminiscent of 'Melanesian' aesthetic.

In Britain, personhood equates with 'independence' which has a high moral value; those who fail to achieve 'independence' are not seen as full members of our society. Children and old people can be excluded from full participation in social life --



and therefore denied personhood -- because of their high degree of dependence on others for financial or material support (Hockey and James 1993). Other possible categories of exclusion are 'the homeless', and 'the disabled' (Murphy 1987). Consequently, as I shall argue below, individuals are people but they are not always necessarily persons. Understandings of the individual and the person as I present them have no necessary universality. Rather, they can be interpreted and linked in diverse ways, in any one socio-historical context. Regarding 'the Western person', the terms appear to have collapsed into each other.

The category of the person

The category of the person was first outlined anthropologically in Mauss's essay '*A category of the human mind: the notion of person; the notion of self*', though he did not develop this work to the same extent as his thesis on gift exchange. Acknowledging the enormity of his subject matter¹⁰, Mauss traces the social and historical development of the notion of 'self'. We are conducted "with some daring and at inordinate speed, across the world and through time...from Australia to our European societies, from extremely ancient history to that of our own times" (Mauss 1985:2), and thus we reach the terminus:

From a simple masquerade to the mask, from a 'role' (*personnage*) to a 'person' (*personne*), to a name, to an individual; from the latter to a being possessing metaphysical and moral value; from a moral consciousness to a

¹⁰ Given in French as the Huxley Memorial Lecture for 1938.

sacred being; from the latter to a fundamental form of thought and action

-- the course is accomplished (Mauss 1985:22).

The 'finished product' in Mauss's essay bears a strong resemblance to the Western person described by Geertz (1986) and many other commentators on 'the person'. We can identify it as Strathern's (1997) Western consumer, yet this analytical model is but one aspect of personhood revealed by the current ethnographic research. It is not my intention to reconstitute Western persons in the form of Melanesian, or any other ethnographically represented, personhood. I do propose giving careful thought to academic and non-academic usages of the terms 'individual' and 'person'. Whereas the terms are assumed to be synonymous, I argue that we need to separate them for both descriptive and analytical purposes.

Ingold (1986) makes a similar point. Opposed to the notion that individuals are purely utilitarian, seeking only self-satisfaction, as one might say of Strathern's Western consumers, Ingold (1986:245-6) rejects the idea that "individuals had an independent, subjective existence outside of and opposed to society." His own view is that "the source of both ... personal identity and ... current purpose lies in the social domain" (Ingold 1986:254), leading him to posit two ways in which the 'person' has meaning in English language use. The first is the jural person who has rights and the second is the category of the self who has control (Ingold 1986:257). While Ingold does acknowledge the 'social' source of 'current purpose', the question of control is awkward. As I go on to argue, like Strathern's Melanesians, the agency for a Western person's actions can be generated by others far more often than we tend to acknowledge, particularly in the case of organ donation.

Two kinds of 'individual'

My own research suggests a slightly different model of the individual/person, focusing rather on two possible meanings, in current English language usage, of the term 'individual'. Interestingly the first meaning tended to surface in my conversations with donor families and recipients, while the second generally turned up in academic literature or official documents of various sorts.

Firstly, in the sense of being unique, individual can mean recognisably 'different from' -- there are no others like this. In this sense, then, an individual is a unique embodied agent, a 'one-off' sample of homo sapiens. So far as human beings are concerned, we each have a visibly different body, even when a close family resemblance might be evident, though the case of identical twins does pose a problem. A second aspect of 'no others like this' has to do with an individual's unique cluster of preferences, habits, dispositions, mannerisms and so on. Here too there can be perceived genealogical continuities with family members ('she has the Smith temperament', 'his father used to sit just like that'), or habitual continuities with people who share our employment, interests or outlooks ('all ballet dancers walk with their feet turned out'). I am not aware of any ethnographic materials which suggest either understanding of 'different from' is not broadly universal, and I do not think I am proposing anything very controversial. What I am suggesting is that, wherever they are, people can usually 'tell each other apart', though the emphasis given to displaying one's individuality/uniqueness is not necessarily prioritised everywhere to the extent it is in contemporary Britain. My use of the term individual draws on this

sense of *difference*, present in Ingold's (1986) and my own understanding of the person.

In its second sense, as single, individual can mean '*separate* from' -- individual sweets may be identical in composition and appearance, but they are all separate from each other. So far as human beings are concerned, it may *appear* obvious that we are all separate from each other; every body and therefore every person is bounded by, and stops at, its own skin. The notion lends credence to individualism as a paramount political doctrine, where the individual as separate from, and more important than, the wider social group, is the prominent understanding of the term (Cohen 1994:168). This kind of individual is contrasted "against its social and natural background" as the one in opposition to the many, where the latter is an abstract concept -- 'society' or 'culture' or 'environment' (Geertz 1983:59).

Apropos of this, it is not my intention to imply the presence of some form of higher order of entity, for example 'Society', in opposition to the person, or even the individual, as they are discussed here. Where I do use the word 'society', it describes not a thing, not a reified abstraction, but "a process *going on*" (Ingold 1986:121). We might, however, wish to ponder the possibility that the bestowal of rights to those who are citizens separates out a particular kind of (jural) individual from the social person, and opposes the former to 'the nation state'. At the same time, we cannot assume universality for this meaning of 'individual'; its application in any social context would have to be carefully investigated.

Similarly, political individualism has a long history in Britain (e.g. MacFarlane 1978); understandably, we may well be at a loss to imagine how it is possible to be

different from, but not necessarily separate from, others. Nevertheless, any discussion of individuals in Britain would have to acknowledge the two indigenous meanings, and explicate their usages. In particular, it is to the second kind of 'one', the one as an *indivisible* individual, that we attach rights of all sorts, hence the term 'individual rights'. Where I wish to specify this second kind of *separate* one, I shall use the term *jural individual* (cf. Ingold 1986).

To restate, then, I am suggesting that we can understand individual to mean different. As its ordinary descriptive plural form I will use the term 'people'. Analytically, this kind of individual can also be a 'person' in the manner I am about to discuss. But there is another kind of 'individual' as separate. I am calling this the 'jural individual' and would argue that, as autonomous and bounded units, 'jural individuals' cannot be persons.

The model of Western personhood presented in anthropological literature is, I maintain, this jural individual of British, and quite possibly north Atlantic, individualism, whose liberty "has become the cornerstone of Western political thought and practice" (Gittings 1984:9). Mauss (1985:21) himself indicates this, commenting on the significance of seventeenth- and eighteenth-century political thought concerning individual liberty whereby the *personne* acquired independence, autonomy, freedom, and the right to direct communion with God. Early in the nineteenth century, under the influence of the philosopher Fichte, individual consciousness was made "the category of the 'self'" and now, finally, each of us has "our 'self' (*moi*), an echo of the Declaration of the Rights of Man" (Mauss 1985:22 and n37).

On this latter point, it will be recalled that Mary Wollstonecraft, “the first major feminist” (Brody 1992:1), was sufficiently moved by the gender inequalities of her day to produce ‘A Vindication of the Rights of Woman’ ([1792] 1992), as the cries of ‘Liberty, Equality, Fraternity’ wafted across the English Channel. Almost 200 years later, Midgley was similarly moved to point out that the “whole idea of a free, independent, enquiring, choosing individual, an idea central to European thought, has always been essentially the idea of a male ... taking for granted the love and service of non-autonomous females (and indeed often the less enlightened males as well)” (Midgley 1984:51, cited in Lukes 1985:299; cf. Hockey and James 1993). From a position of late twentieth-century Western feminism, we should not fail to keep in full view the partial rendering of the jural individual discussed by Mauss, barely a decade after the extension of voting rights to women in Britain in 1927.

A broader notion of personhood

Mauss’s essay on the person is not without its critics, several of whom contribute to a commemorative volume (Carrithers, Collins and Lukes 1985). Pertinent to my own research, Carrithers (1985) contextualises Mauss’s subject matter in relation to the intellectual development of French sociological thought; especially its emphasis on bounded, harmonious, organised wholes. Indeed, this sort of balance and harmony resonates in the concluding pages of ‘*The Gift*’ (Mauss 1990) to which we turn in Section Two. However, only Taylor (1985:278 and passim) hints at the possibility that Mauss’s ‘person’ is not a ‘person’ at all. So, what is a person?

An early definition from Radcliffe-Brown (1940:193-4) distinguishes a kind of individual as "a biological organism" and a kind of person as "a complex of social relationships." This resonates with Taylor's more recent formulation:

Being a person cannot be understood simply as exercising a set of capacities I have as an individual ... I only acquire this capacity in ... human linguistic interchange ... in a certain form ... that of my culture; and I only maintain it through continued interchange ... I become a person and remain one only as an interlocutor (Taylor 1985:276).

Aspects of both arguments could be critiqued from a cross-cultural perspective, if one were aiming for a broad, analytical definition of personhood after the fashion of Leach's (1991) 'marriage as a bundle of rights'. They appear to address corporeal personhood, taking no account of conceptual or metaphysical persons. Neither take account of "the brokenness of bodies" (Schenck 1986:51, cited in Diprose 1995:210), which require medical or surgical intervention in order to exercise their capacities or participate in the process of composition. Conversely, a common significant feature is sociality -- personhood derives from belonging to and participating in social life. Ingold (1986:246-7) proceeds further when he suggests that people are constituted through social relations; social life is "the very process of composition," a process which cumulates a biography. Thus:

if we identify persons with the trajectories of their past experience, that is with their particular cumulative biographies, we must admit first that no person can be quite the same from one moment to the next, and second that there is no obvious point at which we should begin. No complete

biography would start with the birth of its subject [since the story follows on from other lives which have shaped it]. (Ingold 1986:107)

Ingold (1986:263) emphasises the point, borne out by my own research, that “the constitution of persons is a process that is continuous and that cannot therefore be regarded as the working up of a raw material into a finished, ‘moulded’ product.” Of course, in this ‘process of production’ called social life we do not all constitute each other in similar ways or to equally significant degrees. One most unusual way is in the transacting of human tissue and organs. Section One of this chapter has introduced my argument that the anthropological model of ‘the Western person’ cannot be applied unreflexively to analyses of bio-technologies. Section Two takes this a stage further, to my point that human tissue and organs cannot be analysed as if they formed a homogeneous category. Different kinds of ‘bio-gifts’ offer different connective potentialities which can be discerned by examining people’s perceptions of particular transactions. Consequently I argue that, while the transacting of actual body parts may not create a ‘distinct kind of person’ in Strathern’s (1997:302) sense, it does effect a profound change to the persons who are intimately involved. By way of illumination, I draw on studies of bio-technologies generated within both anthropology and welfare and health care scholarship. The latter have been strongly influenced by Mauss’s theory and so we return to *The Gift* and its application to ‘gifts of life’, reviewed in the light of Carrier’s (1995) analysis of Western gift and commodity forms.

II Mauss's Theory of Gift Exchange and Social Solidarity

The Gift (1990) is over three quarters of a century old, yet its central argument remains interwoven with ongoing academic discourse about the apparent opposition between so-called 'gift societies' (non-Western) and 'commodity societies' (Western).¹¹ Drawing on a culturally and historically diverse range of literature, including reports of gift exchange practices in Polynesia and Melanesia (e.g. Malinowski 1922), Mauss concluded that non-Western societies employed the exchange of gifts for the purpose of, for want of a better term, social cohesion. These practices were embedded in "the system of total economic services" and gave expression to religious, juridical and moral institutions (Mauss 1990:3). Gift exchanges bound people together in obligatory giving, receiving and returning because the gifts were animated with the spirit of the giver, a force "both mystical and practical ... that ties clans together and at the same time divides them, ... constrains them to carry out exchange" (Mauss 1990:73). In Maussian terms, the *raison d'être* of gift exchange was to create and maintain a network of social relationships which facilitated the economic distribution of goods and services. The two processes were embedded within each other (Mauss 1990:46). In effect, the system of exchange was about the ongoing maintenance of the whole group in both productive (economic) and reproductive (kinship) senses.

Systems of these kinds differed greatly, Mauss argued, from what he saw around him in his own Western European social setting, and this reveals the political underpinnings of his work, outlined by Douglas (1990). Influenced by his celebrated

¹¹ The labels 'gift' and 'commodity' societies are as awkward as non-Western and Western, but I can think of nothing better. The reader may assume inverted commas round all such contested terms throughout this thesis.

teacher, and uncle, Emile Durkheim, Mauss sought to offer a critique of late nineteenth/early twentieth-century English political theory rooted in utilitarian and individualistic values. As a counter measure Mauss proposed, in effect, a welfare system based on the form of morality he saw operating in 'gift economies'. 'They' had moral persons whereas 'we' had independent individuals yet, Mauss argued, 'we' could be like 'them' if only we tried.

While the conclusion to Mauss's essay resounds with undue idealism and romanticism in twenty-first century Britain, it remains a powerful statement about the nature of human relationships. Later twentieth-century scholarship has been drawn to what Mauss saw as the cohesive potential of gift exchange, upon which he himself was moved to remark, ensuring *The Gift* a prominent place in welfare policy discourses and studies of bio-technologies in Britain. R. M. Titmuss, an influential scholar of welfare policies, laid the foundations when he applied Mauss's thesis to his authoritative study of blood transactions in 1970.

'The Theme of the Gift'

In *The Gift Relationship* (1970) Titmuss contrasts the USA's system of purchased blood with Britain's donation system, drawing on Mauss's (1966) theory. Seeking to discredit the commoditisation of blood, Titmuss brought into sharp contrast "the negative, impersonal nature of bilateral commercial exchange [and] the positive, integrative nature of gift giving in the sphere of social welfare" (Page 1996:95). Titmuss believed that any society's social institutions could "encourage or discourage the altruistic ... foster integration or alienation ... [and] allow the 'theme of the gift'

(to recall Mauss's words) -- of generosity towards strangers -- to spread among and between social groups and generations" (1970:225, italics added). For Titmuss, one such institution was the National Health Service's blood transfusion service. The non-monetary transacting of blood, Titmuss (1970:199) thought in rather Hobbesian style, assisted in maintaining community bonds; if they were broken, he argued, the resulting vacuum was "likely to be filled by hostility and social conflict." Titmuss acknowledged that few blood donors in Britain were motivated by "complete, disinterested, spontaneous altruism" (1970:89). Blood donors who participated in his survey entertained notions of reciprocity, to be fulfilled should they ever require a blood transfusion in the future (Titmuss 1970:239), yet the 'gift' remained for him 'altruistic'.

The Tyranny of the Gift

Sque and Payne (1994) have examined Mauss's ([1966] 1993) theory in combination with more recent writings from an anthropological perspective (Gregory 1982; Parry 1991) on the dichotomous model of 'gift' and 'commodity' exchanges. Noting the influence of Christian moral principles in Western societies, Sque and Payne (1994:47) compare the very favourable public attitudes towards organ donation in Britain with cross-cultural moral evaluations of gift exchange, located firmly in opposition to the workings of market transactions (cf. Parry 1989; cf. Taussig 1980). Although Sque and Payne acknowledge Parry's (1989) comment that both systems of exchange "can be tainted with suspicion" they nevertheless conclude that "organ transplantation is sociologically and psychologically related to the dynamics of gift

exchange, *as monetary re-imburement for organs is outlawed* in developed countries” (Sque and Payne 1994:47, italics added).

Unlike Titmuss (1970) writing on blood donation, the question of obligation is prominently foregrounded by Sque and Payne (1994) in their study of solid organ transactions, and compared with Mauss’s ([1966] 1993) discussion of the obligation to give, receive and return gifts. In the particular context of human organ transactions, the presence of obligation has been called ‘the tyranny of the gift’ (Sque and Payne 1994:48: cf. Fox 1988). When one considers the nature of the object which has been given, human organ transactions can be regarded as creating tyrannies, obligations, debts, which can never be repaid. Nevertheless, and following Titmuss (1970), Sque and Payne’s (1994) theorisation of organ transactions exhibits a favourable moral evaluation of these ‘gifts’, consonant with the promotional materials reviewed in Chapter One. Yet applications of Mauss’s theory in contexts which privilege the contrast between Western forms of ‘gifts’ and commodities, rather than that between different systems of exchange economy, have produced results not necessarily consistent with Mauss’s intentions.

According to Parry (1986:453-6), Mauss’s elliptical writing style and inaccurate first translation (Mauss [1966] 1993) have exacerbated the situation, rendering Mauss’s arguments extraordinarily flexible; close comparative reading reveals significant differences between the translations. I have favoured the later translation (Mauss 1990) which appears more in keeping with Parry’s (1986) convincing critique. Wherever possible I endeavour to cite the copy scholars have used when discussing Mauss’s theory. Similarly, Mauss’s formulation of the theory,

its translations, and their applications are inevitably filtered through each scholar's academic or political pre-occupations (Parry 1986), the current work being no exception.

The main interpretative difficulty relates to the difference between what I shall term, for convenience's sake, 'Maussian gifts' and 'Western gifts', illuminated by Carrier's (1995) attention to Western forms of exchange. Secondly, there is the presumption that all tissue and organ transactions can be analysed in exactly the same way. I shall show that there are differences between kinds of tissue, and differences between kinds of transactions. When these differences are appreciated, considerable scope remains for applying Mauss's theory to analyses of bio-technologies.

For purposes of analysis, the terms 'gift exchange' and 'commodity exchange' are a misleading shorthand. It will be helpful at this juncture to put aside the term 'gift' and adopt instead 'thing' – encompassing objects and/or services (cf. Sahlins 1972: 138). Similarly, speaking, the things one might call 'Maussian gifts' encompass the full range of a spectrum of exchange practices envisaged by Mauss.¹⁰ At one end

¹⁰ My thanks to Tim Ingold for this important reminder.

III A Maussian Framework for the Analysis of Human Tissue and Organs

Drawing on Mauss's juxtapositioning of 'gift' as opposed to 'commodity' exchange systems, the examples from Titmuss (1970) and Sque and Payne (1994) demonstrate the classification of human tissue and organs as 'gifts' *because they should not be treated like commodities*. The distinction operates only insofar as they should not be bought and sold, what I will call *commoditised*. According to Titmuss (1970) the system in the USA was morally inferior to that in Britain. Similarly, regarding organs, an OPCS (1992) survey showed 93% of respondents thought financial incentives inappropriate; on the other hand, the British Kidney Patients Association (1992) reported that 52% of respondents favoured grants for funeral expenses, to be made to the donor's family (cited in New et al. 1994:42-3). But the absence of a monetary value does not render human tissue and organs 'gifts' as Mauss intended the term. Possibilities remain to treat them in the same manner as commodities, *as if* they were, what I shall term *commodified*. It is no co-incidence that I found human organs being commodified most frequently in the very settings where they are literally detached and re-attached, that is hospitals, located in a health care context increasingly permeated by the politics and practices of the economic market.

For purposes of analysis, the terms 'gift exchange' and 'commodity exchange' are a misleading shorthand. It will be helpful at this juncture to put aside the term 'gift' and adopt instead 'thing' -- comprising objects and/or services (cf. Strathern 1988:136). Strictly speaking, the things one might call 'Maussian gifts' occupied the mid range of a continuum of exchange practices envisaged by Mauss.¹² At one end

¹² My thanks to Tim Ingold for this important reminder.

systems of 'total services' involved inalienable things and at the other systems of market economics involved alienable things (Parry 1986:457), within which category we must, according to Mauss's understanding of them, include altruistic gifts. This becomes apparent in Carrier's (1995) exclusive focus on Western economies, mainly the USA and Britain, where the capitalist exchange form predominates, and where a different connotation of 'gift' has emerged from that studied by Mauss in 'other' economies of exchange.

Carefully tracing socio-historical processes, Carrier argues that, in Western societies, need and obligation, and the transactions they motivate, have come to be perceived as separate; the same holds for people and objects (Carrier 1995:9-10). Carrier illustrates that gift relations and commodity relations are identified *in opposition to each other* (emphasis added), the former linked with the sphere of friends and family, the latter with the world of work. Finally, the obligations Mauss (1990) identified as being entailed in gift exchange have, in contemporary Western settings, become submerged because they are embedded within a network of familial and friendship relations (Carrier 1995:21) where the exchange of objects or services is regarded as voluntary, motivated by love rather than obligation. Within this schema, the only morally acceptable kind of gift is 'the free gift', the altruistic gift.

Altruism as Alienation

Chapter One demonstrated the high moral value accorded to altruistic giving in Britain, and particularly to the state-sponsored altruism of our welfare services, strongly reflected in Titmuss's (1970) discussion of the Blood Transfusion Service.

Yet Mauss repeatedly stressed that 'gift exchange' was premised on a balance of self-interest and disinterestedness (Parry 1986:456). 'Complete, disinterested, spontaneous altruism' did not foster integration in the societies Mauss studied, nor was the 'theme of the gift' generosity towards strangers. An initial gift may have been given to a stranger, but the purpose of exchange was to turn strangers into allies and supporters. Mauss contrasted altruistic giving with inalienable forms of gift exchange, offering his essay as an indictment of charity, the altruistic gift, the "voluntary, unrequited surrender of resources" which leaves recipients indebted and "does nothing to enhance solidarity" (Douglas 1990:vii).

The people implicated in such exchanges would be the autonomous, jural individuals discussed in Section One. Carrier's discussion can be intertwined with historical analyses of the development of the autonomous individual (e.g. MacFarlane 1978; Gittings 1984; Hockey and James 1993) which has assumed a dominant role in late twentieth-century political philosophy. Significantly, Carrier argues that the opposition of gift relations and commodity relations, and a denial of the former's obligatory nature, are *not so much experiential as ideal* (Carrier 1995:21, emphasis added). They are how we represent ourselves to ourselves, a point made by Ingold (1986) in relation to analyses of altruism "predicated on a certain notion of the subject ... as a discrete individual," a model which has emerged because "we view our everyday life through an atomising ideological glass that presupposes the isolation of the subject" (Ingold 1986:277). As a result, Ingold argues, we represent our involvement with others as external to ourselves, coming between self and other, rather than as implicating part of ourselves, linking self and other. Viewed from this

perspective, altruism is not so much about 'selfless giving', the kind of generous giving exemplified in promotional materials for organ donation. Rather, we can identify it as giving detached from oneself, arising from the alienation of people and things, involving a rather impoverished kind of person abstracted from the obligations of social relations.

The Problem of Reciprocity

Conversely, Sque and Payne (1994:48) argue that human organ transactions do entail obligations, ranging from the "subtle pressures that enhance the obligation to give" to the 'tyranny' of indebtedness felt by organ recipients who "can never totally repay the donor for their priceless gift." Such 'tyranny' (cf. Fox 1988) may cause serious psychological harm to recipients and donor families (Sque and Payne 1994:48). Interpretations of this kind resonate with Parry's (1986:463) comments on Mauss's 'spirit of the gift' (we may read this as what links the gift with the giver). Some anthropologists have found the notion most problematic in contrast with the idea of obligation, manageable under the rubric of reciprocity (e.g. Sahlins 1972).

Parry argued that, when the gift is *dana*, its spirit precludes reciprocity (1986:463). An offering given to Brahmin priests, *dana* embodies the sins of the giver; "a kind of sacrifice," it must be totally alienated from giver and recipient because of the dangers it carries (Parry 1986:460-61). A similar perspective can be attributed to health care professionals about organ donation. Human organs can be interpreted as 'carrying the death' of the donor to the recipient, provoking feelings of

guilt, which motivates health care professionals to control or prevent contact between the donor family and the recipient lest the guilt is exacerbated.

At the same time, organ recipients often feel they wish to make some form of return for their gift. However, recourse to the notion of reciprocity and hence to 'repayment' of the debt (Sque and Payne 1994:47-48) -- with its implicit assumption of an obligation discharged, cancelled -- cautions us to beware the pervasive influence of our Western economic model of exchange.

Here the governing principle is "an exchange of alienable objects between people who are in a state of reciprocal independence that establishes a quantitative relationship between the objects exchanged" (Gregory 1983:100). Even if we allow that human organs can be treated as if they were commodities, Gregory's definition of reciprocity in commodity relationships does not transfer to human organ transactions. Attempting to incorporate reciprocity in a quantifiable mode is impossible when the thing given is "inestimably precious" (Verndale and Packard 1990). During the present study, a number of organ recipients remarked to me "how do you repay someone for saving your life?"

The question of recipient indebtedness was something Mauss (1990) particularly addressed when he turned to welfare provision in the concluding section of his essay, but the inability to repay or discharge an obligation was not, for him, the tyranny, since his primary focus was not the 'quantitative relationship between the objects exchanged'. The gift exchanges of which Mauss wrote have been described by Gregory (1983:101) as "an exchange of inalienable objects between people who are in a state of reciprocal dependence that establishes a qualitative relationship between the

transactors.” For Mauss, it was the inability of altruistic gifts to maintain relationships which was the tyranny.

During the current study, I found that relationships were being established between the families of organ donors and the recipients of those organs. Other studies of organ transactions report similar findings (Sque and Payne 1994; Cunningham 1999; Alnaes, personal communication); studies of tissue transactions report participants perceiving some kind of connection (Titmuss 1970; Konrad 1999). An analytical appreciation of these feelings of connection can be found in Strathern’s (1988:xi) remark that “classification does not inhere in the objects themselves but in how they are transacted and to what ends.” If we also concern ourselves with the ways in which human tissue and organs are transacted, and to what ends, we begin to see that dichotomous models -- inalienable/alienable, gift/commodity -- and the homogeneous classification of all tissue and organs are unhelpful strategies for analytical purposes.

The Connective Potentialities of Human Tissue and Organs

In Titmuss’s (1970) study of blood transactions we noted that a form of balanced reciprocity was entertained by some donors; one day they themselves might need to receive a transfusion. Other donors offered broader and less concrete reasons for giving blood; “some sense of obligation, approval and interest; some feeling of ‘inclusion’ in society” (Titmuss 1970:238). Titmuss was thus drawn to visualise blood donation enacting a sort of generalised anonymous sociality, motivated by a sense of obligation. In a more recent ethnographic analysis of ova donation (Konrad 1999:652)

many donors reported equally nebulous but rather stronger perceptions of 'something' that linked them with the women who would receive their ova. Konrad (1999:943) concluded that ova donors "enact forms of relatedness as the sociality of anonymity." We need not associate these exchanges with 'jural individuals'; they may feature the transacting of human tissue as anonymous (Strathern 1997) but those who give do express, albeit vaguely, a perception of enhanced participation in social life. The women Konrad (1999) interviewed could even envisage a direct link with another woman as recipient.

Sque and Payne's (1994) theoretical review evokes a much more specific form of connection, as does Cunningham's (1998) empirical study. Acknowledging that a relationship is established between donor families and recipients in the transacting of human organs (cf. Abrahams 1990), these writers give some emphasis to its emotional significance. Donor families may wish to know that the recipient recovered from the operation; recipients may wonder who their donor was; either party to this extraordinary transaction may wish to communicate with the other, or even meet. In this regard, Sque and Payne (1994:48) note Titmuss's (1970) comment about the transacting of human organs, when he suggested that something of the donor's self or personhood might be envisaged as accompanying the organ. He is describing, in effect, an inalienable thing in Mauss's terms, though the description does not necessarily apply to all 'bio-gifts'.

Instead, we need to rethink the inalienability and alienability of things in terms of degrees. Describing two different sorts of objects given during Samoan marriage celebrations, Mauss used the terms '*immeuble*' and '*meuble*', derived from medieval

French law pertaining to different forms of property (Weiner 1985:213, citing original publication Mauss 1923-24:156; see Mauss 1990:8-10). As a critique of misplaced analyses which interpreted exchanges of both kinds of object as balanced reciprocity, Weiner (1985:213) comments about the varying degrees of significance attached to the objects; not only was one kind, fine mats, held in higher esteem than the other kind of locally produced or Western manufactured goods, but the fine mats were ranked in relation to each other according to their social histories (cf. Appadurai:1986). Weiner (1985:213) argues "the full range of the statement that [a] fine mat makes about its own genealogy ... cannot be repeated with any other"; thus each mat is unique and not replaceable.

Weiner's insight resonates with the examples given above, where different kinds of human tissue enact differing degrees of connection. From my own research, I will show that major solid organs, rather like the fine mats, carry a genealogy, a significant factor in understanding the connection between the families of organ donors and the recipients of those organs. Helman's (1991:100) comment is apposite: he suggests that human organs carry their own history into the bodies of their recipients, as "hidden narratives of another life and another death." I am terming this history 'intangible substance', and I am arguing it cannot be detached from the physical substance of the organ. While it may be possible to hide these narratives -- they can be submerged in certain contexts -- they are never erased. Organ recipients know that someone had to die in order for their lives to be extended, that they live because they carry another's physical substance. I have found that they often wonder about their donor and the bereaved family, using chance snippets of information to

sharpen an otherwise nebulous image, writing their own narratives. And what of donor families? They are a part of that intangible substance, that narrative of another life and another death. From them it cannot even be hidden. They keep photographs, treasured objects, a lifetime of memories shared with someone whose physical substance now resides in another body (see Plates 9-14). Though unknown to each other, I argue that organ recipients and donor families are inevitably implicated in a mutually constituting relationship engendered through the intangible substance of the organ in which they both participate.

Summary

The application of gift exchange theory to bio-technologies is embedded within wider socio-cultural understandings of the nature of gifts. Chapter One addressed how the notion of altruism has exerted a tenacious influence through history on attitudes to private and state-sponsored welfare in general. In this chapter, we have seen its effect on perceptions of human tissue and organs as gifts. Baldly stated, they are gifts because they cannot be commodities. Blood was the first widely utilised 'gift of life', followed by other sorts of tissue, the major solid organs, and reproductive materials. It is my argument that all these materials were conveniently but erroneously labelled as 'gifts of life' by way of a cluster of common features; they are all bodily substances, used in a biomedical capacity to create, enhance or extend life, and they are (imagined to be) freely given -- that is they are both given voluntarily and with no expectation of any return. The primary classificatory marker, however, is their opposition to commodities.

Focusing on human tissue and organs in terms of what they do in a connective capacity, the degrees of relationality they provoke, other classificatory labels are available. 'A kind of property' has been proposed as offering fresh insight into our understanding of human tissue and organ transactions. 'Property' and persons can be linked with widely differing degrees of connectivity. Human organs may be amenable to treatment as if they were commodities but they simultaneously resist the process of personalisation suggested by Strathern (1997:295). It is my argument that human organs personify their donors, through the 'hidden narratives of life and death' which they carry from one body to another, implicating donor families and recipients in a sociality which challenges the orthodox model of the Western person. As I shall argue, the form of personhood to emerge from my own research is best represented as a shifting process, permeating and permeated by, a sociality which extends beyond the detached 'betweenness' of relations 'after the fact' of personhood.

This shifting process is presented in Part Two of my thesis, which addresses the issues of anonymity, voluntarism and reciprocity, respectively. In its Introduction, I describe in more detail the donor families and organ recipients whose participation in the organ donation/transplantation process formed the substance of my research, along with elements of the transplant programme's organisation and administration which strongly influenced their perceptions of that participation.

How can I become an organ donor?

Simply complete this organ donor card and carry it with you at all times so that should it become necessary your wish to donate your organs to help others will be known to your doctors.

Even if you register on the NHS Organ Donor Register you should still inform your relatives who will be asked for permission to remove organs in the event of your death.

BUT PLEASE DISCUSS YOUR DECISION WITH YOUR RELATIVES.

Please also fill in the form in this leaflet and send it to the NHS Organ Donor Register. This confidential Register will give doctors and nurses a more efficient method of discovering whether a deceased person wanted to donate their organs.

There is no need to complete this form if the DVLA has printed on your driving licence that you are registered as an organ donor.

Must my relatives be involved?

If you carry a donor card and/or your name is on the NHS Organ Donor Register, technically your organs may be used for transplantation without consulting anyone else. But, in practice, doctors will not remove organs if your relatives object.

Donor Card

I would like to help someone to live after my death.

Let your relatives know your wishes.

Once a patient has been certified as brain stem dead, the relatives will be asked to agree to organ donation. This has to be done within hours because the organs must be removed very soon if they are to be used for transplantation.

Your relatives will only be able to fulfil your request to be an organ donor if you have previously made them fully aware of your wishes.

SO, TO BE SURE THAT YOUR ORGANS ARE DONATED AFTER YOUR DEATH, PLEASE DISCUSS THE SUBJECT WITH YOUR RELATIVES AS SOON AS YOU DECIDE TO BECOME AN ORGAN DONOR.

Will my relatives know who receives my organs?

Strict confidentiality is maintained throughout the donation and transplantation process. However, your relatives will normally be told how your organ donation was used and the outcome of the transplant operations.

Why is it necessary to discuss organ donation with my relatives so soon after my death?

For medical reasons, a decision on organ donation cannot be left too long. So, while it may be a difficult subject for relatives to handle, if they know that the deceased definitely wished to be an organ donor, then the burden of a decision to allow organ donation to proceed will be much less.

What is more, organ donation can often help relatives deal with their own feelings in a positive way if they know that, by giving their consent, they are helping to give life to another person. And that, therefore, they could be sparing another family the grief that they themselves are experiencing.

Your questions on organ donation Answered.

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LIFE

DON'T KEEP IT TO YOURSELF

This leaflet includes a form to register on the NHS Organ Donor Register

Donor Card

I would like to help someone to live after my death.

Let your relatives know your wishes.

Life - don't keep it to yourself

Organ donation can be a difficult subject to think or talk about.

Most people do not want to contemplate their own death. Nor do bereaved relatives find it easy to decide on the donation of the organs of a loved one who has just died. The same goes for the doctors and nurses who may have fought to save the patient's life.

Medicine has developed so rapidly over the past 20 years that transplant surgery is now an established and successful method of treatment - one that not only saves lives in the short run but which can allow the patient receiving the organ to live a full life for many years to come. But far more patients could be saved if there were more donor organs available.

BY ALLOWING YOUR ORGANS TO
BE USED FOR TRANSPLANT AFTER YOUR
DEATH, YOU WILL BE GIVING SOMEONE
ELSE THEIR LIFE BACK.

This leaflet aims to answer some of the most commonly asked questions about organ donation.

What is organ donation?

It means making it clear that you agree that after your death, organs from your body may be used for transplantation to help other people. In many cases, this will save lives. In others, it will allow blind people to see again. Or it will free patients from other forms of long and painful treatment, such as spending hours a week on a kidney machine.

What organs can be donated?

The major donor organs are the kidneys, heart, lungs, liver and pancreas. In addition, heart valves, other muscular tissue and,

above all, the cornea - the front part of the tough outer shell of the eyeball - can all be used for transplantation. This means that one donor can help many other patients.

Who will receive the organs?

Recipients are chosen on the grounds of need and by blood group and, if necessary, by tissue characteristics. There is a waiting list for organ transplants because the demand exceeds the supply.

Who can be an organ donor?

Anyone could be a donor. But, for the major organs, it is only those people who have suffered serious accidents (mostly head injuries) who actually become donors.

Will the fact that I am a known donor affect the treatment I receive in hospital?

Definitely not. The doctors involved in your treatment will not be the ones interested in organ donation. In any case, the prime concern of all doctors and nurses is for their living patients and they will make every attempt to save their patients' lives. Only after they are satisfied that nothing more can be done will the question of organ donation be raised.

Will I really be dead when they remove my organs?

Yes. Before a donor organ is removed from a patient, doctors establish death has taken place with a series of tests to ensure the brain stem does not function. These are carried out twice by two senior doctors, acting independently from one another, who work under a strict code of practice and who are not involved in the transplant process. The time of death is the time of the second set of tests.

The brain stem is nerve tissue that makes up the lowest part of the brain and connects with the spinal cord. It is a highway for messages travelling between the brain and the rest of the body through the spinal cord.

and it controls the basic workings of the body as a whole. When the brain stem stops functioning, a person cannot be regarded as alive.

What happens after the tests?

Once doctors are sure that brain stem death has occurred, the donating patient is kept on a 'ventilator' which keeps the heart beating in order to circulate oxygen. This maintains the organs in a healthy condition until they are removed.

Will all the organs be used?

All healthy organs are normally used. It will be up to the doctors responsible to decide whether or not - and which - organs can be successfully transplanted to another patient. In most cases, organs can be used despite advanced age and previous illness. If you have suffered from certain illnesses, this could rule out the donation of some organs but not others.

Will the organs be used for research?

In the rare cases when organs cannot be placed with a recipient, if the relatives have given prior permission, the organs may be used for research. No organs will be used for experimentation unless you have decided to leave your body to medical science and made the proper arrangements.

Will my body be damaged by organ donation?

When any organs are removed, it is done by a skilled operating team. The body is treated with respect and dignity throughout. And once the operation is over, there will be no sign that any organs have been removed.

Will the funeral be delayed?

No. Arrangements for the funeral can be made as in any case of death. The body can be viewed after the organs have been removed, and the funeral need not be delayed in any way.

When are the organs removed?

Only when death has taken place for certain. Two doctors, working independently, and who are not involved in the transplant process, will carry out a series of proven, and strictly monitored tests to confirm brain death. As in any operation, the body is treated with respect and dignity throughout. You will be reassured to know that the funeral need not be delayed.



May I donate my organs to be used for research?

Yes - but this cannot be arranged through the Register. If you would like your organs to be used for medical research, please tell your relatives or doctor. No organ will be used for research without consent.



"I believe in living life to the full. That's why I think it would be good if, when I die, some parts of me can be used to give extra life to someone else. Better than going to waste, surely?"

"The offer of a donor ten years ago gave me my life, and gave me a life to live - without that gift of life, I would not be here today. All the things that I could not do before now come easily, thanks to someone's generous gift."



"My life changed dramatically immediately after the transplant. I went back to work as a cargo supervisor on the Swansea Docks 16 months after my heart transplant and worked for 15 years until my retirement."

"We feel comforted to know that some good may come from our tragedy - and that our grief will help to bring joy to somebody else."

For more information about organ donation and transplantation write to: UKTSSA, Fox Den Road, Stoke Gifford, Bristol BS12 6PR. For more copies of this leaflet call Freephone 0800 555 777

00911

Join the NHS Organ Donor Register and give the gift of life

DONOR CARD HOLDER OR NOT - WE NEED YOUR HELP



The gift of life is a gift without price

Death and organ donation. They can be difficult issues to think about, let alone talk about. And if it's hard for us now, think how our relatives might feel, and the medical staff who fought for us right till the end. Nobody finds it easy to let go.

Adding your name to the NHS Organ Donor Register means that you join a nationwide, confidential list of people, held on a central computer database, who are prepared to be organ donors after their death. The register helps to bring donors and transplant recipients together quickly. It also makes it much easier for relatives to accept organ donation when they know that their loved one made the effort to register.

By joining the NHS Organ Donor Register now you could help save, or dramatically improve someone's life. To a chronically, or fatally ill person, it's a gift without price.

We realise that organ donation is a subject that raises many questions and here are some of the answers you might need before you register.

Who can be a donor?

Anyone, even the elderly or people who have had various diseases, can be a donor in the right circumstances.



Will my hospital treatment be affected if they know I am a donor?

Absolutely not. Hospital staff will fight to save your life right up till the end. And anyway, the doctors who look after you are not the same ones involved in the transplant process, so there is no question of divided loyalties.

CUT ALONG THIS FOLD AND STICK

How to join the register

To join the NHS Organ Donor Register, simply fill out the form opposite and send it back. You won't need a stamp, but you should tell your family. Legally, relatives don't have to give their consent to organ donation, but in practice doctors ask them. It will be much easier to reach a decision if they know your wishes; it might also comfort them to know that your commitment is being fulfilled. The register is completely confidential and your details will never be passed on.

The Donor Card, carried by many people, will continue to be used, but everyone who carries one should also register - Donor Cards cannot always be found at the crucial moment.



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You might not know...

Nearly 3,000 organs are transplanted in this country each year.

As well as life-saving operations, there are over 2,000 sight-saving corneal transplants carried out each year.

Heart, liver and kidney transplants which were once huge scientific breakthroughs are now commonplace. And as medicine advances, the types of organs that can be transplanted have increased. They now include organs such as lung, pancreas and small bowel.

The option of donation after death can be extended beyond organ donation to a much larger group of donors who can give tissues. For example, corneas can restore sight and heart valves can save lives through their use in the treatment of heart disease.

There is no maximum age for some donations so healthcare professionals would decide each case.

Having an existing medical condition does not necessarily prevent a person from becoming a donor.

Again, the decision is taken by healthcare professionals.

The huge success of transplantation means that even more donors are needed. The most

successful transplants come from organs donated from within the recipient's own ethnic group because of the importance of matching tissues in organ donation.

People are still dying while waiting for a transplant.

If you require any more copies of this leaflet please call the new Organ Donation Literature Line on 0845 60 60 400 (calls are charged at local rates). If you have any further enquiries about organ donation, please write to the UKTSSA, (United Kingdom Transplant Support Service Authority), Forth Road, Stoke Gifford, Bristol BS34 8BP.

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ODMAC1

Organ Donation.
Everything
you need to know.

Organ Donation. So life can go on.

Over 5,000 people in the UK are waiting for an organ transplant that will either save or dramatically

improve their lives. Many people each year will die before they can receive a transplant. But as many people as possible need to be prepared to donate after their death to help reduce the waiting lists.

Millions of people already carry donorcards or are on the NHS Organ Donor Register, expressing their wish that their organs should be used for transplants when they die.

Many more have already taken the decision that they would like to help others in this way but they may not have told anyone how they feel about organ donation or expressed their wishes through carrying a donorcard or joining the Register.

Facing up to the death of a loved one is hard. Having to make a decision about organ donation, unsure what that person would have wanted can cause extra pain.

The best way to make sure your family and friends never find themselves in this situation is to talk to them now. Tell them that you would like to be a donor. You can carry a card and join the Register. Even more important is making sure everyone knows that you want to be a donor.

What to do.

Above all, make sure that those closest to you know what you want, should the need ever arise. That way, they'll have one less ordeal to cope with.

Carrying a donorcard and/or putting your name on the Register confirms your decision to be a donor if the time ever comes.

The NHS Organ Donor Register is a nationwide, confidential list held centrally on a database of people, who are willing to become donors after their death. The Register helps to bring donors and transplant recipients together quickly. It is maintained by the NHS.

If you wish to join the NHS Organ Donor Register please complete the attached form.

You will also find a donorcard attached to this leaflet if you wish to carry one.

TEAR AND MOISTEN GUMMED EDGE

You are much more likely to need a transplant than to become a donor. If you are prepared to consider accepting a transplant for yourself or your family, it seems only fair to play your part by being willing to be a donor.

How is donation handled?

The idea that our death may help others is comforting. Looking back, friends and families often feel better knowing that some good has come out of the tragedy.

But, understandably, people want to know how the process is handled. For instance, if the time ever came is the welfare of the donor priority? The fact is, doctors' and nurses' entire training and commitment is based on doing everything possible to save a patient's life.

Organs are only removed when two doctors, working independently, have carried out a series of strict tests and monitoring to confirm brain stem death. These doctors are not part of the transplant team and they have no connection with organ donation.

The removal of organs is carried out with the same care and respect as any other operation.

The funeral need not be delayed.

NHS Organ Donor Register

donorcard

I want to help others to live in the event of my death

DETACH BEFORE POSTING

PART TWO

PARTIAL PERSPECTIVES ON THE ORGAN DONATION AND TRANSPLANTATION PROCESS: Introduction

I The Research Participants

By way of introduction to the central part of my thesis, this section offers further biographical information about the donor families and organ recipients I interviewed. I then go on to discuss 'discontinuities' in the organ donation and transplantation process which rendered variegated accounts of their own participation. However, I wish to draw attention here to one important issue regarding the processes of 'becoming a donor family' and 'becoming an organ recipient' which I present in Chapters Three to Five.

The donor families and organ recipients I interviewed reported ambivalent, not to say deeply ambiguous, feelings about their participation in the performance of organ donation and transplantation. However, there were marked differences in their manner of relating that participation. My interviews and telephone conversations with donor families were highly emotional and very draining. As often as not, I found myself crying with whoever I was speaking to. Even when happy memories of the deceased donor were being recalled, there was a bitter-sweet poignancy in the remembering (cf. Battaglia 1990:197), and little or no opportunity to 'look on the bright side'. In contrast, when organ recipients told their stories, there were occasional tears; some situations were more emotional than others; but overall, these conversations were scattered with humorous anecdotes or joyfully recounted

examples of ‘what I am able to do now’.¹³ Listening to recipients, I was reminded of the historical portrayal of transplantation’s development as a ‘heroic struggle’ (above, Ch.1). Consciously or not, these recipients related ‘becoming an organ recipient’ as a struggle to be endured and ultimately overcome, particularly signposted by ‘The Assessment’ and ‘Getting the Call’ (below, Ch.5).

Donor Families

The first meetings I had with donor families took place in the library of a Cambridge college, where the British Organ Donor Society was holding its 1997 Convention. Steve and Claire had been sitting next to me during the afternoon’s formal presentations, and I simply asked them if they would be comfortable about speaking to me. They agreed, and introduced me to another couple, Tom and Catherine, to whom they had “got talking” at lunchtime. What ensued was more of an open discussion than formal interviews, not least because we all retired together to the library, but also because I wished to reassure these families that I would not impose either my own research agenda or my own assumptions about what bereaved people need or want. At that same Convention, Rita and Conrad approached me about my research, and offered to help. Though Steve and Claire declined further participation in my research, the other two couples gave me their addresses.¹⁴

Late in 1997, Rita and Conrad visited me at home during a trip to Scotland, while early in 1998 I visited Tom and Catherine’s home. Our conversations here lasted two to three hours. Tom and Catherine’s only child, John, was 24 when he died

¹³ For an example in written form, see Plate 8.

¹⁴ Steve and Claire are fictitious names, at this couple’s request.

and became a multi-organ donor in 1995. Rita and Conrad's son, Philip, was 41 when he died in 1996. He too became a multi-organ donor. Both couples evinced a need, well documented in bereavement literature, to talk about their sons. Added to this need, both couples had apparently gone through such traumatic events during and after the donation event, I left them to relate their stories to me in their own ways. This involved showing me their store of memorabilia and photos, carefully placed in albums, which I was invited to look through.

Over and above our meetings, we communicated by letter and frequent telephone conversations. Such research methods hardly exhibit anthropology's standard 'total immersion' in the daily lives of participants, yet I established a strong rapport with both couples, whom I now regard as friends, still exchanging phone calls, letters and Christmas cards. Rita has often sent cuttings from magazines or newspapers; usually they have upset her a great deal not only because, as promotional instruments for organ donation, they focus entirely on saving the lives of potential recipients through stressing the need for more donors --as Rita put it, "for more people to die" -- but also because they present a picture of donor family comfort and support which jars painfully with her own circumstances.

Ongoing communication with both these couples gave significant insights into the possibility that donor families' views can change as they move through bereavement and reflect back on their participation in the donation process. Sadly, neither of these couples have come to feel that their participation brought any measure of comfort, not least because of a lack of communication with their donor co-ordinator, and with recipients who benefited from their acts of donation.

Organ Recipients

I was granted access to organ recipients at one transplant unit, where staff selected a small number of out-patients who lived within reasonable travelling distance for me to visit. Letters of introduction, Information Sheets about my research, and Consent Forms for participants, were posted by the staff.¹⁵ All these recipients agreed to take part. Interviews ranged from one to three hours and I conducted three with each recipient. One recipient met me on the occasions when I visited the Out-patient Clinic to interview staff; another chose to meet in a convenient and quiet bar in Edinburgh city centre; I visited the others at their homes. As a condition of REC approval to conduct my research with patients from this hospital, I signed a declaration to maintain their, and the hospital's, anonymity. Meeting other organ recipients at BODY Conventions is the main way this has been achieved, though I regret the fact that this second group of recipients has receded, unrequested, into anonymity.

Broadly speaking, all the male and female recipients I interviewed or met informally ranged in age from early 40s to late 60s. At the time of our meeting, they were between one year and ten years 'out from their transplant', indicating how long ago the operation had taken place. Among them, every major solid organ had been transplanted. Family backgrounds were diverse; recipients were single, married, divorced, with and without children. In the accounts related below, all names of organ recipients are fictitious. Further, I have occasionally attributed comments from one actual recipient to a fictitious other. Lastly, though I do name organs received by

¹⁵ These are requirements of RECs. For detailed discussion of the application process, see journal articles in Appendices 7 and 8.

recipients, where I have felt it necessary to clarify particular stories, it should not be assumed that the recipient relating that story necessarily received the organ named.

II Organisation Aspects of the Transplant Programme

As the Introduction to this thesis noted, the transplant programme engages a heterogeneous and numerous range of health care professionals employed in administratively autonomous hospital units throughout the UK. Efficient implementation of the programme is dependent upon a high degree of inter-unit co-operation, facilitated at the present time by the United Kingdom Transplant Support Service Authority (UKTSSA) and a somewhat patchy network of co-ordinators. Though the cross-bodily transfer of human organs can be made to appear as a unified process, organisational aspects of the transplantation programme sustain discontinuities which impact upon families of potential or actual organ donors, organ recipients, and health care professionals, not necessarily in comparable ways. I discuss these discontinuities next, moving on to give a brief description of the articulating role of co-ordinators.

Discontinuities in the Transplantation Process

Beginning with perceptual discontinuity, which I found to be most significant, analytically and ethnographically, the donation and transplantation process can be divided in different ways with regard to the participation of those involved. My research foregrounds the accounts of donor families. These could be discussed in relation to their relative's death, or the act of donation, or their interactions with health care professionals. One of these divisions was emphasised to me by a transplant surgeon. We had been discussing my research finding, that what I am calling the

realms of the donor and the recipient were bounded in such a way as to separate the organ donation and transplantation process into two distinct parts. The surgeon expressed concern over this finding, insisting that the two parts are inseparable. However, when I introduced explicit examples to support my finding, he wished to separate the issues surrounding the death of a relative and the family's interactions with ICU staff, from those of the act of donation and interactions with donor co-ordinators. We were each perceiving a separation between parts of the process, but perceiving them in different places, probably a result of our own different positionality. I willingly acknowledge that any part of the whole process can be separated from any other part, for example for the purpose of examining or improving practices in a specific area, and that any actual changes may or may not impact on the process as a whole (e.g. Cunningham 1998). Nevertheless, I would argue that the intensity of bereavement lends significant weight to individual processes of interpretation, and that bereaved people cannot neatly cordon off 'this bit' of the process from 'that bit'.

The increasing significance of perceptual discontinuity can be traced in the *Code of Practice* which has set professional guidelines in the UK over the last two decades. The first version (Health Depts. 1979) was titled '*The Removal of Cadaveric Organs for Transplantation: A Code of Practice*', wherein discussion of donor care, diagnosis of brain death, and organ removal were interspersed. The most recent version (Dept. of Health 1998) separates the process. It is titled '*A Code of Practice for the Diagnosis of Brain Stem Death: Including Guidelines for the Identification*

and Management of Potential Organ and Tissue Donors'.¹⁶ Comparing these titles, a de-emphasising of organ removal is apparent; the latter version explicitly bifurcates the process. In the annotated 'step by step' plan (pp. 18-19), also split between two separate pages, clinical diagnosis of brain stem death is listed before consideration of any patient's eligibility as a donor.

Underpinning this conceptual discontinuity, spatial discontinuity stems from the highly fragmented nature of health care today, whereby different conditions or diseases are treated by different health care professionals in specialised hospital units. The circumstances under which 'the gift of life' is given dictates that the giver and receiver are located in different places. Potential organ donors are located in accident and emergency or intensive care settings, clinically and administratively disconnected from the transplant units where recipients are to be found.¹⁷ These units can be in the same hospital, though they will more frequently be in different hospitals which can be very distant from each other. For discussion purposes, I am calling these the donor and recipient realms. One of the most notable factors underlined by a consideration of spatial separation is that, in the recipient realm, the attention of transplant unit staff and the family of a potential organ recipient is called towards that recipient's 'fight for life'. The deaths of potential recipients drive the campaign for organ donation. Concurrently in the donor realm, the attention of ICU staff and a potential donor's family is called towards a similar 'fight for life' and, where efforts fail, towards that person's death. In these circumstances, the attitudes of health care professionals

¹⁶ Brain stem death has become the accepted term, to differentiate this from clinical diagnoses of whole brain death, or higher brain death, which is not legally recognised as 'death'. The latter condition would include people in persistent vegetative states.

¹⁷ For this thesis, I address intensive care units only, since most of the donors whose families participated in the research died in these units.

towards their patient's relatives, and the attitudes of the bereaved family towards their deceased loved one, may overwhelm any concern about giving 'the gift of life' to others.

A third form of discontinuity is temporal, and relates to engagement in the donation/transplantation process. While organ donors and recipients are both 'patients' of hospital units, recipients are visibly engaged with the process for a longer period. Potential recipients are referred to transplant units from other specialist areas of care. Once referred, they are carefully assessed regarding their suitability for a transplant operation. Once accepted, they are placed on a waiting list and may have to wait many months, even years. Where a suitable organ becomes available and the transplant operation is successful, recipients nevertheless require substantial clinical support for the rest of their lives. At the least, they will return to the transplant unit as out-patients every year and can contact the unit or their own general practitioner in the event of ill health.

In contrast, while someone may have carried a donor card for many years, he or she will become actively engaged with the process suddenly, as a result of external or internal physical trauma, and technically leave the process as a deceased donor within a very few days, perhaps weeks. Family members are engaged with the process in parallel with their relative's involvement but they are not 'patients', nor are they primarily (or even) regarded as the ones who make the donation; these acts of exclusion have major ramifications for their own, and other people's, perceptions of their participation in the donation process. So far as donor families are concerned, their participation is lifelong, because their memories of their loved one and his or her

act of donation endure for life. It may also be the case, though longitudinal qualitative studies are conspicuous by their absence, that curiosity about, and a sense of connectivity with, recipients is also lifelong.

Practices which sustain the gap between the realms of the organ donor and the recipient are not necessarily the result of any deliberate, unified strategies adopted by health care professionals. In an article critiquing the ideology of hospice care which has come to impose an idealised way of dying on patients, Hart et al. (1997:73) argue that carers are not "individually responsible for this new form of social control," yet control emerges, sustained by practice. The senior surgeon to whom I spoke was concerned to emphasise that donation and transplantation are parts of one process, and strongly disagreed with my argument that they are separated. Nevertheless, a form of discontinuity was expressed explicitly by a co-ordinator when I was preparing to obtain ethical approval for my research. While links between the realms were apparent to me, and one of the issues I particularly wished to investigate, the co-ordinator advised me to separate them for my presentation to the local research ethics committee (REC) and in discussions with ICU staff at other hospitals. Her reasons related to the fragility of relations between intensive care and transplant units, a fragility which resides in the need for public reassurance that every effort is made to save the life of the potential donor.

Herein lies a fundamental tension in the donation/transplantation process. While ICU staff and TU staff both aim to save lives, achieving this aim in a transplant unit requires the failure of that aim in an intensive care unit. Consequently there can be a degree of ambivalence among ICU staff towards organ donation.

Despite their discontinuities, the two realms must be linked to facilitate the transacting of human organs. Metaphorically speaking, the donor and recipient coordinators provide a bridge.

The donor and transplant process has developed in accordance with a piecemeal fashion since the early 1960s when the coordinator would function as both donor coordinator and transplant coordinator. Over time, the two responsibilities came to be split into two separate roles, and donor coordinators have increasingly assumed a centrality in the whole process. This is apparent from the *Code of Practice* (Dept. of Health (1998)) which governs the outgrowth of both work areas and the role of coordinators for transplantation. The first two versions (Health Dept. 1979, Dept. of Health (1983)) refer to 'co-ordinators' but there is no specific mention of co-ordinators. In the latest version (Dept. of Health (1998)) a page is devoted to outlining the role of co-ordinators, and their function function was UKTSA. Therefore, several references are made to the role of co-ordination in the version:

However, the latest version uses the term *transplant co-ordinators*, reflecting a shift away from two separate disciplines – donor co-ordinator and transplant co-ordinator, the division of roles remains though in similar manner with the co-ordinators now will undertake both functions (UKTSA 1998: 33). Donor families I met expressed disapproval of the term *transplant co-ordinator* because it appears to stress the transplant aspect of the process, a central theme running through the thesis. Further, I found the term difficult to verbal practice and influenced the process of people who became organ donors. Therefore, the terms *donor co-ordinator* and *recipient co-ordinator* are employed. *Recipient co-ordinators* tend to work within the recipient

The Role of Co-ordinators

Co-ordinators are generally located and financially sustained from budgets in the recipient realm. Many were formerly nurses. Involvement of co-ordinators in the donation and transplantation process has developed in something of a piecemeal fashion since the early 1980s, when one co-ordinator would function in both realms. Gradually the responsibilities came to be split into two separate roles, and donor co-ordinators have increasingly assumed a centrality to the whole process. This is apparent from the *Code of Practice* (Dept. of Health 1998) which governs the diagnosis of brain stem death and removal of organs for transplantation. The first two versions (Health Depts. 1979, Dept. of Health 1983) refer to 'the transplant team' but there is no specific mention of co-ordinators. In the latest version (Dept. of Health 1998) a page is devoted to outlining the role of co-ordinators, and their liaison functions with UKTSSA. Thereafter, several references are made to the role of co-ordinators in the process.

However, the latest version uses the term *transplant co-ordinators*, reflecting a shift away from two separate designations -- *donor co-ordinator* and *transplant co-ordinator*; the division of roles remains though in smaller transplant units one co-ordinator may still undertake both functions (RSCE 1999:38). Donor families I met expressed disapproval of the term transplant co-ordinator, because it appears to erase the donation aspect of the process, a central theme running through this thesis. Further, I found the term dramatised a clinical practice and submerged the presence of people who receive organs. Hereafter, the terms donor co-ordinator and recipient co-ordinator are employed. Recipient co-ordinators tend to work within the recipient

realm; their role is presented in Chapter Five. Donor co-ordinators more often travel between the realms; their role is discussed next.

The Donor Co-ordinator

Within the donor realm, donor co-ordinators assess the provisional suitability of potential donors and arrange for clinical screening tests. The *Code of Practice* recommends that co-ordinators are informed about a potential donor at an early opportunity, not least because he or she may not be suitable, for clinical reasons, in which case relatives do not have to be approached (Dept. of Health 1998:12). Where a potential donor is suitable, co-ordinators perform a variety of administrative tasks. These include liaison with UKTSSA which allocates organs to transplant units; obtaining formal authorisation for organ removal from a patient's relatives; and arranging all practical aspects of the removal operation, including transportation of the organs to their allocated transplant units. Early notification to co-ordinators is therefore important, logistically. Allocating organs on a national rota basis, and arranging removal and transplant operations, are complicated and time consuming procedures, particularly in the case of multi-organ donation, where more than one transplant unit is involved. Any significant time delay could mean that the donor's heart spontaneously ceases to beat before the removal operation can be conducted. Furthermore, the heart, lungs and liver have to be transplanted quickly. The designated transplant unit has therefore to locate the potential recipient, who must travel to the unit and be prepared for the transplant operation while the removal operation is being conducted on the donor.

Given their central role in organ donation, one might wonder why donor co-ordinators are not located in intensive care units.¹⁸ I was given two reasons for this. The first was logistical. Unlike transplant units which are highly specialised centres, few in number and widely dispersed, there are many more ICUs, where donors would be located, but each unit would in all likelihood deal with a very small number of donors, if any, on an annual basis. From this point of view, administrative centralisation makes sense. The second reason gets into the problematic area of ethics and morals. At a weekend Convention of the British Organ Donor Society (BODY) in 1997, the Friday afternoon was devoted to presentations by and for health care professionals. One presenter outlined the 'retrieval system' in Spain, where health care professionals (most often a doctor) are employed, on an additional and part-time basis, as donor co-ordinators. They are expected to identify potential donors, not only of solid organs but also of tissue, through regular visits to units where donors might be found, and through scrutiny of the daily death reports, since some tissue can be removed from patients who died of cardiac arrest. They are termed non-heart-beating donors.

On the Friday evening of the Convention, I joined a group of ICU nurses whose assessment of the Spanish system was not favourable. One said that to have a member of hospital staff deliberately looking for people who could become organ donors would be like "death stalking the wards." Another told me, "my unit's staff have enough problems coping with a patient's death, without someone earmarking potential donors in advance." She also said that contacting the donor co-ordinator

¹⁸ The exception is the London region.

was "admitting defeat." Many health care professionals regard death, particularly of younger people, as a defeat and seek to focus on doing everything possible to save a patient's life. ICU staff also wish to be *seen* to be doing everything possible to save a patient's life. The staff I spoke to about the procedure in Spain all wondered how families would feel about the presence of a donor co-ordinator in the hospital. Would it to them also conjure up images of "death stalking the wards," and cause concern that not enough was being done to save the patient? As one nurse told me, the transplant programme is based on trust, a significant part of which involves full confidence that everything will be done to save a patient's life. There should be no suggestion that a person is admitted to hospital for the sole purpose of obtaining organs. Ideally, people would recover and return home to their friends and family.

Where it becomes apparent they will not recover, the decision about when to involve donor co-ordinators lies with senior ICU staff. One co-ordinator told me that in her experience being summoned to a unit meant the family had already been asked and had reached a decision in favour of donation. Another said she was "not always successful," indicating an earlier role in approaching a potential organ donor's family.

The need to approach relatives sensitively is emphasised in the *Code of Practice* (Dept. of Health 1998:14) which also notes that relevant training may be valued by ICU staff. Training in communication skills was raised in several presentations at BODY Conventions which I attended, some made by donor co-ordinators. Particular attention was devoted to appropriate management of relatives in intensive care units, and guidelines on sensitive approaches for organ donation. Donor co-ordinators told me of serious distress caused to relatives because of the inadequate

communication skills of ICU staff. The general picture to emerge is that the experience can be traumatic for bereaved families, particularly if it is not well managed by health care professionals.

Among the bereaved families I have interviewed, one of the strongest views to emerge was that health care professionals, including donor co-ordinators, had been unable to communicate sensitively and with empathy. None of the families had been offered information about bereavement counselling, though one young widow told me about an intensive care unit which set up counselling by a member of the nursing staff. The last thing she wanted to do at that time, she said, was to return to the unit where her husband had died. I also learned that co-ordinators might refer people to BODY, which was established to offer emotional support to the families of organ donors. Conversely, a number of health care professionals, including donor co-ordinators, expressed reservations about BODY. Reasons for this resided mainly in the founders, John and Margaret Evans, having 'a very particular perspective', or 'a selective viewpoint', with the implicit assumption that health care professionals hold an objective and totalising knowledge, an assumption I challenge in the next chapter.

ICU staff were not forgiven by the co-ordinators I interviewed. They were Communication between the realms

Apart from the issue of approaching families sensitively about organ removal, communication between the donor and recipient realms is possible on three different but interconnected levels. Firstly, staff in both realms can be in direct communication with each other. Second, donor families and transplant recipients can be given information about each other. Third, donor families and the recipients of their

relatives' organs can sometimes communicate with each other. On each level the co-ordinators occupy a pivotal role though, on the latter two levels, that role can feature practices which effect and sustain communicative discontinuities.

Communication occurs with staff in the donor realm because co-ordinators recognise the emotional stress involved in caring for organ donors. The co-ordinators I interviewed emphasised that they would write or telephone with basic details about recipients, along with thanks for their work. Particular concern was expressed for operating theatre staff in the donor's hospital, who can often be left "in limbo." They did not know the donor or his or her family, and they may have no contact with the donor's intensive care unit after the operation. Staff who assist with the donor's operation can find the experience unpleasant. One co-ordinator said that, unless she telephoned or wrote to them, theatre staff would have no idea of the "successful end result" of what can be a very distressing situation -- operating on "a dead body." A theatre nurse I met at a BODY Convention reiterated this view. She came to the Convention specifically to get a happier view of organ donation, since she only dealt with deceased donors and never learned about recipients.

ICU staff were not forgotten by the co-ordinators I interviewed. They too would be contacted, to hear about a recipient's recovery. One co-ordinator asked ICU staff to pass on this news to the donor's family, if they telephoned or visited the unit. The co-ordinators I spoke to said they contacted the ICU staff for their own sake, because their work was emotionally distressing. However, the importance of advising them about the success of recipient operations was emphasised at BODY Conventions for another reason. Awareness of the successful outcome of transplant

operations affords the possibility of more favourable support from ICU staff. Co-ordinators I met were, no doubt, genuinely concerned for the emotional well-being of health care colleagues. At the same time, the more general need to promote organ donation among ICU staff cannot be ignored, though it was not an issue I was aware of before I began research on this phenomenon.

The donor and recipient co-ordinators may also communicate basic information to donor families and recipients about each other. In most cases which came to my attention, donor families would most often be given the age and/or sex of recipients. In their turn, recipients would be given the age and sex of the donor, and sometimes the relationship of surviving next of kin, for example a wife.

Donor families and recipients might also communicate indirectly, via the co-ordinators, or directly with each other. I found the latter form much less frequent, and neither form was widely supported among transplant professionals. They argued that either recipients or donor family members can feel themselves to be strongly attached to the other, emotionally involved with the other, and this was regarded as potentially harmful. Since control of communication emanates largely from the recipient realm, the matter is treated fully in Chapter 5.

Education

Beyond the physical confines of the donor realm, donor co-ordinators contribute to public education about, and the active promotion of, organ donation. Promotional leaflets and media articles illuminate a number of themes raised by co-ordinators and other health care colleagues in interviews, casual conversations, and presentations at

BODY Conventions. These themes have a forceful impact on what I am calling the public performance of organ donation. Three promotional leaflets are reproduced as Plates 1-6 (Pp. 75-80) and employed to illustrate various points in this work. Here, I briefly present two media articles which give some prominence to the role of co-ordinators, but reflect very different styles of presentation.

On public attitudes, an article in the *Big Issue in Scotland* (No. 136, 1997) features co-ordinators in Glasgow who inform us that countering the myths which lead families to decline organ removal is “a tough job.” The first myth is about ‘vulture-like’ doctors, who will mutilate or badly treat bodies, only interested in getting organs; seeing the donor’s body after the removal operation alleviates this concern, we are told, an option always offered by these co-ordinators. Further problems arise in the “confusion about brain-stem death,” which many people do not understand, and the anger relatives can feel about a sudden, unexpected death, particularly of a child. Where it is a child who has died, the number of refusals to donate organs “is very high,” but after a death “the time for education is over.” To compound a bereaved family’s distress, a co-ordinator points out that “grieving relatives can live to regret refusing organ donation.”

An article in Sainsbury’s *The Magazine* (Sept. 1995) also featuring co-ordinators stresses the availability of “counselling and support as long as a bereaved [donor] family needs it.” A co-ordinator explains that donor families receive “every detail about a recipient except their name and address” and that “recipients are encouraged to write anonymously to the donor family to express their own thanks ... for most people [donor families] that is enough.”

A new facet of the exchange process is introduced here. In the foregoing section we saw how that process is perceived as fragmented and discontinuous. Now we see the process reach its conclusion; an organ is given and accepted, thanks are returned and accepted. From one perspective, and resembling the dyadic exchanges of the marketplace, the transaction is meant to have been completed.

Summary

To re-iterate the main points of this Introduction, we have seen that many professional people are involved in the donation and transplantation process, itself bifurcated into two distinct realms. Giving the gift of life is not a simple matter of exchange; the transacting of human organs is mediated by a diverse range of health care professionals. Participation was rendered even more bewildering for donor families I interviewed because they encountered a traumatic lack of fit between their expectations, informed by public representations of organ donation, and the attitudes of health care professionals which informed daily practices in the donor and recipient realms.

Reflecting on the organisation of the transplant programme, Sque and Payne (1994) make a particularly apposite point in relation to my study: the role of health care professionals as gate-keepers is not well understood (cf. Fox and Swazey 1974). My own approach to health care professionals treats them as both gatekeepers and participants in the donation/transplantation process.

In this regard, Sahlins's critique of *The Gift* raises two relevant issues.¹⁹ First, Sahlins argued that Mauss understood exchange "in the way it is presented to experience -- fragmented ... into the separate acts of giving, receiving, and repaying" where the *hau* (the spirit of the gift) becomes "mystic cement" used to glue back the fragmented elements (Sahlins 1972:154). Second, Sahlins emphasises the complicating presence of a third party in the exchange process (Sahlins 1972:160-1; cf. Mauss 1990:10-13). The donor families and organ recipients I interviewed certainly encountered the process of organ donation and transplantation as fragmented, as indeed did I; further, health care professionals were regarded as a complicating presence, as the controllers and distributors of information (cf. Sque and Payne 1994:49; Cunningham 1998 *passim*).

As gatekeepers and participants health care professionals are located within distinct and discontinuous clinical realms. Their location and role as carers can affect how they interpret and respond to their participation in the transplant programme, which is discussed in Chapter Three. In turn, the perspectives of health care professionals could have profound effects on how donor families and organ recipients regarded their participation in the process, as I shall show in Chapters Four and Five respectively.

¹⁹ I am not in agreement with Sahlins's first comment.

Chapter Three

Managing the Transplant Programme: human organs as a health care resource

Introduction

Rothfield (1995:174) has argued that “knowledge always arises from a complex of circumstances, practices, related forms of knowledge, and institutional loci. It is not a panoramic view of the world but is always partial, provisional, and located.” This Part of my thesis has two interwoven themes. One presents and accounts for different knowledges of the body within the broad context of the organ transplantation programme. The other theme illustrates what happens when one form of knowledge -- in this case biomedical knowledge -- is privileged over other forms. Thus, I endeavour to untangle the ‘complex of circumstances, practices, related forms of knowledge, and institutional loci’ which give rise to these partial knowledges.

That diverse and even conflicting knowledges of the body can be held by health care professionals, as well as donor families and organ recipients, is illustrated in Section One of this chapter. Priority is given to ethnographic data which both challenges and reflects representations of human organs as either altruistic gifts or commodities. In Section Two, a theoretical explication of different bodily knowledges accounts for the prevalence of the medical model of bodies, among both health care professionals and lay people. In Section Three, I reflect on the significance of the medical model of bodies and organs in the context of investigations into means of resolving a perceived gap between the supply of organs and the demand for them.

I From personhood to anonymity: perceptions of donor bodies

On the medical model of death

Morton & Macintyre have argued that “in the absence of signs of life ... the body becomes *just* a body -- a corpse” (1995:13 emphasis in original), while Gatens writes of the “neutral, dead body” (1983:150, cited in Rothfield 1995:183, emphasis removed). Similar comments were often encountered over the course of the current research, reflecting attitudes held by living people towards their *own* bodies after death. As nothing more than bodies, no longer of significance, one can safely contemplate the removal of organs for transplantation (cf. Richardson & Hurwitz 1995, Papagaroufali 1999 for comments on waste/recycling of bodies and their parts).

In their turn, these attitudes reflect the dominance of a medical and legal model of death, which occurs in an instant; a time of death is pronounced, after which we are left with nothing more than a dead body. Decisions as to when someone is ‘really dead’ vary cross-culturally (Bloch and Parry 1982:12-13). In Britain, historically, death has generally been recognised to require the cessation of heartbeat (but see Powner et al. 1996). Complications have arisen as a result of life-saving and life-sustaining technologies which destabilise long-standing interpretations of life and death, and the boundary between them, as Chapter One explained.

The phenomenon of brain stem death permits a critique of the notion that death is simple to determine, since it amplifies the processual nature of physiological death to an unprecedented degree. The death of a part does not equate with the death

of the whole, something well known to mortuary staff and funeral directors.²⁰ These 'deathworkers', as Howarth (1996) calls them, know that hair and nails continue to grow on the bodies of the dead, and that bodies do not instantly putrefy. Death unfolds over time. Certainly, brain stem death has been accepted for biomedical and legal purposes as an indication that integrated bodily functioning has irretrievably ceased, and its introduction to Britain met no widespread public opposition, such as Lock (1996a; 1996b) has documented in Japan. Nevertheless, its validity remains the subject of debate among biomedical ethicists and philosophers.²¹ From a philosophical perspective, Evans insists that "the spontaneously persistent heartbeat is a sign that the individual is not dead" (1994:6). Similarly, Chadwick argues that "it would seem odd ... to call a corpse an object which still manifests one of the traditional signs of life" (1994:55-56). Youngner (1996:44-47) writes of a 'cognitive dissonance' provoked by medical technology forcing us to choose which signs of life count and which do not, and which is discernible in language use: it suggests that the person dies twice (cf. Lock 1996:220, citing Younger et al 1989).

Never just a body

Official literature and reports about organ transplantation seek to emphasise the ordinary nature of brain stem death, "no different from death as commonly understood" (New et al. 1994:10), the intention being to place public discontent and unease about this kind of death beyond the bounds of 'rational thought' and into superstition or ignorance (e.g. *Big Issue in Scotland* No. 136, 1997). During the

²⁰ My use of the word whole should not be taken to imply the boundedness relating to autonomous, jural individuals.

²¹ See Lamb 1985, Chapter 6 for a lucid discussion.

current research, though donor families found acceptance of their loved one's death very difficult, neither they nor the health care professionals I interviewed expressed doubts about the donor being 'really dead' (but see Keep [1998] and Gill [1999]).

But death is not only a physiological process. When we die, our disconnection from the social world is not instant and total; it is also processual, depending on the perspectives of the living (e.g. Battaglia 1990; Bloch 1971; Bloch & Parry 1982; Connor 1995; Hockey 1990; Metcalf and Huntington 1991; Mulkay 1993; Prior 1989). Even in the face of broad agreement that a body is dead, a matter less easy to ascertain than one might imagine, it is seldom, if ever, 'just' a body to other (living) people. On the contrary, the bodies of the dead provoke the endowment or negation of meaning, manipulable through the positionality of the observer. To declare dead someone whose body manifests all the commonly understood signs of life -- a heartbeat, blood circulation, body warmth, skin colour, breathing -- is profoundly unsettling to the social process of death, not only for lay persons but also for health care professionals.

In Britain, as Machado (1998:4) argues, the descriptive terminology applied to bodies reflects their perceived connection to, or disconnection from, their social context, and indicates the correct social behaviour towards them. During the present study, when it came to caring for and talking about the living bodies of people declared dead, ambiguities and uncertainties were apparent among donor families and health care professionals. My own uncertainties also manifest in my use of shifting terms to describe these bodies/people, because I could not decide on one which seemed universally appropriate though 'deceased' seemed reasonable, in most

situations, as a general term, prompting me to emphasise that while specific rules of behaviour may well be fixed to specific terms, the application of those terms is by no means uniform.

Not Dead but Deceased

Discussing the materiality of the body, Morton and Macintyre (1995:13) argue that “a body is more than its materiality, which is why, in order to be a person, it must possess life,” a statement which could be challenged in the case of people in persistent vegetative state, where family members argue that there may be a living body but ‘the person they knew’ is no longer there (*Scotsman* 12.4.96). As the discussion in Chapter Two argued, there is more to being a person than having a living body.

Without wishing to appear flippant, my own research clearly illustrates that being dead need not imply ‘having a dead body’. The bodies of potential organ donors are not dead; if they were, organ transplantation would be pointless. While the patient has been declared brain stem dead, the body’s tissues and organs remain living for hours or even days. Knowingly or not, the health care professionals to whom I spoke tended to mask this ambiguous status with the word ‘viable’ -- organs are kept ‘viable’ by the life-saving technology to which the patient had been connected in an effort to save his or her life. That machinery circulates oxygenated blood, and maintains the balance of other bodily fluids and chemicals, until a decision about the use of the patient’s organs is reached.

Even in situations where it was generally understood that the body was ‘dead’, I learned that great care would often be taken by health care professionals to choose

words which did not upset the family of a deceased patient. (Significantly, they did use the word 'patient' frequently, to prevent identities being revealed to me, but I have also observed its use as a handy generic label, as I use 'donors' and 'recipients'.)

Recalling Youngner's comment about the inappropriateness of terms which indicate dead bodies, any application of the terms 'corpse' or 'cadaver' to the bodies of those declared brain stem dead met with strong disapproval. 'A corpse' has lost much of its social subjectivity as a former person (Machado 1998:4). Cadaver seems to me to have been regarded as more of a medical term, denoting "an object with medical or biological connotations rather than social aspects" (Machado 1998:4). I encountered its frequent application, in texts devoted to transplantation, and as a descriptive term employed by academics and health care professionals who spoke of 'cadaver donation'. Indeed, having occasion to refer back to fieldnotes from 1995, I realised I had employed the term myself, and its use was not totally absent in conversations with donor families.

When speaking directly of their relative, donor family members tended to prefer 'body', and they usually added the name of the donor, speaking of "Philip's body" or "John's body." When they were recounting their experiences before that body was released by the hospital, they tended simply to say "Philip" or "John." The bodies of organ donors, far from being 'neutral', were regarded as embodying loved ones still connected with their family members. The circumstances of their deaths tended rather to retrospectively reinforce their identities as generous young people whose deaths were sudden and totally unexpected, but whose foresight and consideration meant that other deaths would be prevented.

In their dealings with the relatives of their patients, health care professionals even tended to eschew the word 'body'. Describing their communications with bereaved relatives, nurses told me they would use either the patient's personal name, for example 'Susan', or a relationship term, for example 'your son', when talking to parents. Intensive care unit staff may have known a potential donor for a very short time, and if someone was brought into a unit already unconscious, there would have been no interaction with 'a person'. Nevertheless, the ICU staff I met were aware that their patient was a member of a family, someone's daughter, someone's dad, and nurses in particular had to spend time with the family, offering what comfort they could. This care with words applied even when they seemed to contradict what the health care professional 'really knew'. One co-ordinator explained how, when she speaks to the family of a potential donor she knows she is discussing 'a dead body' but, as a mark of respect, never uses that term in front of the relatives.

'Backstage' hospital humour can be much less respectful, rendering the caring image of health professionals questionable (Sudnow 1967, cf. Hockey 1990, Howarth 1996). I was not permitted access to contexts which might have revealed similar behaviour, but the point I wished to make concerned the interactions of health care professionals and the families of potential organ donors. In the next section, I turn to the management of organ donors by health care professionals, as it was recounted to me by their families, and by health care professionals themselves.

From Person to Body

At what point, under what circumstances, does a 'person' become detached from his or her body, or the body from the 'person'? Machado (1998:4) draws attention to the processual nature of this detachment; I would emphasise its oscillating qualities, thrown into particularly sharp relief in the context of organ donation. Until a decision has been reached about the use of organs, the status of the potential donor is somewhat liminal -- "betwixt and between" (Turner 1967: Chapter 4) -- or even in a Derridean sense, both and neither (e.g. Culler 1979:esp.165-66 on *differance*). From the perspective of transplant professionals, he or she literally embodies scarce and valuable resources which could save the lives of their patients. Careful medical management is essential, otherwise organs could be damaged and useless for transplantation. At the same time, ICU staff are not dealing with a living person as a patient. This can create tensions, because the deceased patient is still someone's relative and should be (but is not always) treated with the sort of care the family would wish. Tom and Catherine told me how their son was left alone on two occasions. Nurses had come into the cubicle to carry out routine care, and had asked visitors to leave until they were finished. But they had not let the visitors know that they could return to John's bedside. His parents felt this was wrong. Someone should have been with him all the time. It is not that they thought John was alive. They simply felt he should not have been alone. At this point in time, 'John' and 'his body' were still intimately connected so far as his parents were concerned.

However, family members are not the only people who think deceased patients should not be left unattended. The following examples concern treatment of what I

shall now call 'the donor's body', after the removal operation. This matter, I discovered, is the subject of controversy. In one case, a nurse from a transplant unit was given the opportunity to observe a 'retrieval operation'. Once the organs had been removed by the transplant teams, the donor's body was left alone in the operating theatre. The nurse said she was appalled that "the body" had been left lying alone. She could not understand how theatre staff could do that; paradoxically she apparently saw no problem in her use of 'the body' as a descriptive term. Another nurse, recalling a similar situation, was moved to go into the theatre and hold the donor's hand for a while. When she looked into "his empty body," she realised "he was really dead," though it was still awful to look down into "an empty, open body." Her feelings were exacerbated by the knowledge that "the patient's parents" were waiting to see "him" before they left the hospital. These donors may have been really dead, but they still called forth strong emotional responses, and provoked uncertainties regarding their exact classification -- the transition from a 'person' to a 'body' is fraught with ambiguity.

The apparent abandonment of these donors' bodies was given some perspective by an operating theatre nurse. He told me that when a patient dies during an operation, the staff take a half hour break as a mark of respect, before closing the incisions and performing last offices; the gap between organ removal and closure of the donor's body reflects a similar mark of respect, from the perspective of the health care professionals involved. However, this view was rejected by the donor families I know, who were deeply distressed at the idea that donors' bodies were being left alone. A donor's father went so far as to say that management of the body after the

operation was being treated as a minor consideration, left to junior staff, or "the next shift." The practice of leaving care of deceased patients to 'the next shift' has been noted by Sudnow (1967: Ch. 3) in his study of two hospitals in the United States. Among the British participants in my study, the only nurse prepared to assist with removal operations in her hospital told me she stays to perform last offices for her deceased patients, though her unit's senior staff "hassle me to get back to caring for the living."

An emphasis on care of the living, this time of potential organ recipients, was also apparent in a conversation with a transplant surgeon, for whom the ambiguous status of the donor body permits a conceptual resolution to the problematic of operating on 'a dead body'. I asked the surgeon if he had to employ any particular strategies for coping with the removal operation. A potential organ donor is brought into the operating theatre with a beating heart, which has to be stopped as part of the removal operation, and actually removed if it has been donated. It struck me that this might be a difficult thing for a surgeon to do, knowing that the heart will not be re-animated in this patient's body. The surgeon said he had not found it easy, but he had learned what worked for him. Conceptually, he began the operation on 'a patient' and finished with 'a dead body'. At the same time, he felt he was going to 'retrieve' an organ which was 'already' his patient's. By the time a surgeon reaches the potential donor's hospital to remove the organ(s), there is a strong degree of certainty that it will be suitable for his or her patient -- who is currently being prepared for the transplant operation back at the surgeon's own hospital. Far from being an "anonymously produced object [which] becomes part of a store on which others

draw" (Strathern 1997:302), human organs for transplantation are 'produced', brought forth, in highly exceptional circumstances. They are cut out of the bodies of specific people, by specific people, for specific people.

Talking to the same surgeon, I was struck by what was no doubt his genuine commitment to his patients and, simultaneously, his concern to show respect for the organ donors who permitted that commitment to go on. Unfortunately, not all surgeons demonstrate such thoughtfulness, as one instance related to me by an ICU nurse illustrates. It was very late in the evening and the nurse was sitting with the parents of a young male organ donor; they had chosen to stay in the intensive care unit while the removal operation was conducted. At one point the door was pushed open, a young man put his head round the door, and introduced himself as "one of the retrieval team." He asked if Mr X, the senior surgeon, had arrived yet. When the nurse replied that he had not, the young man said this was his first retrieval, and he was really pleased it was going to be supervised by such an eminent surgeon. The nurse told me she just looked at him, and said, "these are the donor's parents," at which the young man "went a bit red, said 'oh', and left the room, without so much as an apology." Before encountering the donor's parents, the surgeon appears to have effected a conceptual disconnection of the person and the body, viewing the latter, in this instance, as a learning opportunity, to enhance his surgical skills under expert guidance.

II Agency, Inscription and the Transplant Programme

Endeavouring to elucidate the unstable nature of bodies, in so far as they will not 'stand still' long enough to bear permanent inscription (Lock 1993), I am indebted to Crossley's (1996) synthesis of Merleau-Ponty's 'body-subject' and Foucault's 'body-power'. The kinds of bodies/persons emerging from the current research exhibit elements of both these extreme positions but also encompass the continuum which flows between them, so that particular 'subjectivities' manifest, shift, and change, according to their particular inter-relationship with other bodies/persons.

Rothfield's (1995) comments on the substantive body are also illuminating since she challenges, at some length, the biomedical assumption that bodies exist as essential objects. While bodies 'exist' in the form of substance, Rothfield argues there is no neutral, a priori body to which we have access since nothing can be objectified, named, inscribed, outside of language. Our very perception of bodies as matter, and their definition through inscription, are inextricably linked in the process which produces meaning. Yet there is no single meaning since, in order to define, we inevitably take up positions in relation to the body in question. Different positions produce different kinds of knowledges about the body and, I would emphasise, no-one need be committed to a single position. At the same time, certain positions and the knowledge they produce assume an authority derived from their articulation with other dominant discourses. One such is biomedical knowledge. To better understand how this form of knowledge produces particular kinds of bodies, I return to the concepts of 'body-subject' and 'body-power'.

Merleau-Ponty (1962, 1965) developed the notion of the 'body-subject' in response to a dominant Western philosophical assumption that bodily action arises from prior and separate acts located in a mind (the subject) which somehow stands outside and in superior opposition to the body that is its object; similarly, the 'body-subject' does not relate to its world as a subject to an object. Instead, body-subjects belong to and are part of the world; our very way of being-in-the-world (Heidegger 1962) is through embodied actions (Crossley 1996:100-101). Though this embodiment can be regarded as *living through the body*, one's substantial body is absent from explicit awareness since it is not so much an object of attention than an orientation centre in relation to our environment (Diprose 1995:209).

Pain, however, affects this habitual mode of being-in-the-world; the mind and body are separated to the extent that one is conscious of bodily pain (Leder 1990 cited in Diprose 1995:209). Schenck (1986) takes this further by suggesting that pain or illness, the 'brokenness' of bodies, invites the care of others. From this we may conclude that pain or illness alters how we interpret and respond to our own or other bodies; they alter our habitual modes of being-in-the-world. To put it another way, one's subjective position in relation to that body has shifted. Significantly, health care professionals already occupy a professional position which responds to the brokenness of bodies, to whom, Schenck (1986) argues, we give over responsibility for their repair. This brings me to consider the location of agency.

Superficially, Merleau-Ponty's 'body-subject' bears scant resemblance to the jurat individual discussed in Chapter Two, but on closer inspection we find that both are accorded autonomous agency; 'body-subjects' act. Indeed Merleau-Ponty could

be accused of overemphasising agency while ignoring the effects of power; for a socio-political understanding of the latter we can turn to the work of Foucault, though here the body is apparently bereft of agency and is entirely acted upon (Crossley 1996:104-5). The theoretical conceptions of 'body-subject' and 'body-power' apparently oppose each other (Levin 1989; Grosz 1993), yet in Crossley's (1996:99) view, they are not only compatible but "mutually informing and complementary." This is illustrated through Foucault's own later conceptions of agency and power, where power consists "in an attempt, by one agent, to conduct the conduct - Foucault likes the word play - of the other" (Crossley 1996:105 citing Foucault 1982:220). In other words, the successful application of power requires not a person who acts and a person who is acted upon, but rather "a person who acts and a person who acts upon those actions" (Crossley 1996:105). This suggests balanced, reciprocal agency, what we might term the mutual constitution of persons in daily life (Ingold 1986:263), or "communicative intersubjectivity" (Crossley 1996:110), sharply contrasting with the forms of *subjection* Foucault attended to (e.g. 1977).

Foucault's notion of the body has been described as "a passive receptacle of historical and political forces ... functioning to the requirements of the social system" (Crossley 1996:104 citing Levin 1989). But rather than *passive* bodies which permit themselves to be acted upon, Foucault is more accurately describing *docile* bodies which permit themselves to be managed (O'Neill 1985:132-3). Management is achieved through "the materiality of power operating on the very bodies of individuals" (Foucault 1980:55), in other words by "direct and active attempts to control, direct, delimit and co-opt the actions of the body" (Crossley 1996:105).

However, the direct application of power to bodies is normally disguised since it is routed through the organisation and control of space; in particular Foucault discusses practices which enclose, divide, and differentiate spaces within which bodies can be rendered controllable and functional (Crossley 1996:106-7; cf. Foucault 1976, 1979), to the extent, I would add, that compliance is regarded as beneficial; otherwise, resistance may be offered (Foucault 1981, 1982; cf. Crossley 1996:107). How then is compliance perceived to be beneficial?

Crossley's (1996:111) example of how power operates upon bodies is apposite since he suggests we have a largely medical awareness of bodies and their parts, influenced by a historically contingent web of discourses to which we all subscribe, knowingly or not; these discourses articulate with other health related practices which regulate our daily lives and to which we submit because we primarily identify ourselves through a medical model of our bodies. By and large, when we become ill, we expect and accept health care; we submit ourselves to the treatments offered by an existing biomedical regime because we wish to get better. Even those who turn to 'alternative' forms of treatment nevertheless seem to hold an ideal model of 'the healthy body' and experience 'deviations' from that as requiring intervention of some kind. Biomedicine apparently offers us a radical degree of control over our bodies, in its extreme form over death itself. Yet as prolonged life has become a supreme value, and our dependence on clinical treatments has increased, it could be argued that control over bodies has actually passed into the hands of biomedicine's practitioners (White 1995:22), which brings us back to the medical model of the body.

That model assumes an abstracted, objective 'everybody' in which biomedicine merely intervenes (Rothfield 1995), disregarding the significance of a particular body's location within a relational matrix of other bodies which imbue each other with meaning (Diprose 1995:205-6). What we have is the 'everybody' of the anatomy textbook; more appropriately to the present study, it is the anonymous body which yields equally anonymous organs for the transplant programme.

Summary

The 'disconnectedness' of bodies from each other is presumed in Western metaphysics and embedded within biomedicine's everyday ways of thinking, speaking and acting. Part of the 'habitus' of the clinic, such everyday practices may well be effected with no strategic intention (Bourdieu 1977:72-73). It has also been argued that such disconnection prevails between bodies and their parts, in so far as organs are regarded as "free-standing entities" (Strathern 1997) functioning in the manner of commodities outlined in Chapter Two. Yet unlike commodities, where transactions can be based as much on desire as on need, and unlike Maussian exchange, where the transactors desire "the personal relationships that the exchange of gifts creates, and not the things themselves" (Gregory 1983:19), potential organ recipients very much need 'the thing itself'; the alternative is death. In another sense, there is a need for organs; they are in 'short supply'. Section Three reviews means by which organs are currently, or in the future might be, obtained for transplantation, contextualising the perceived shortage of organs and the current emphasis given to what health care

professionals widely term 'cadaver donation'. Here, the commodity metaphor is evident yet, like the gift metaphor, it is also unstable.

III Increasing Demand, Declining Supply: the nemesis of the transplant programme

Organ transplantation has rapidly become a standard form of treatment for diseases of the major solid organs. Having proved beneficial in an increasing number of medical conditions (Richardson 1996:88), we can reasonably assume this trend will continue. In a recently produced promotional leaflet for organ donation (see Plates 5-6), we learn that nearly 3,000 organ transplants are conducted in Britain each year. However, the leaflet also states that “over 5,000 people in the UK are waiting for an organ transplant.”²² Transplantation’s “huge success,” its inclusion of ever more kinds of organ and tissue, and its now commonplace position as a form of treatment all amplify the need for more organs. The demand for organs is, if not infinite, then certainly amenable to growth, as evidenced by comparing figures from the Annual Reports of the United Kingdom Transplant Support Service Authority (UKTSSA), currently responsible for maintaining an administrative database for the transplant programme. The number of potential recipients waiting at 31 December 1995 was 6083; at 31 December 1996 it had risen to 6355 (UKTSSA 1996:6).²³ The 1998 Report recorded a total of 6539 people waiting at 31 December 1998 (see Box 1).

It has been remarked that waiting lists do not necessarily reflect the “real need” for transplants and therefore the number of operations which would be done, given an unlimited supply of organs (RCSE 1999:19); transplant professionals apparently impose quantitative control. Certainly, those interviewed in the present study emphasised their transplant unit’s rigorous selection of potential recipients (see Chapter 5). The RCSE (1999:7) report noted that “the number of cadaveric donors

²² The figure appears not to include suspensions from the waiting list; see Box 1.

²³ Excludes kidney patients in the Republic of Ireland.

has remained at a plateau of 900, reached in 1990” but does not propose a concomitant ceiling on waiting list numbers, a suggestion made by one transplant co-ordinator I interviewed. Instead, “(i)ncreasing the potential number of donors remains ... fundamental to policy formulation” (RCSE 1999:7).

BOX 1

Transplant Activity 1998, UKTSSA***

Number of organ donors during 1998	847*
Number of organs	2965**
Recorded waiting list for transplants at year end- active	5383
suspended	1156

* including 26 from overseas

** including 30 from overseas

*** Statistics prepared by the UK Transplant Support Service Authority from the National Transplant Database maintained on behalf of the UK transplant community. (ISSN 1464-4444)

The paradox of applying a commodity metaphor to human organs

Richardson has noted “the constant refrain of shortage” in public and academic discourses about organs for transplantation (Richardson 1996:88), remarking that “too much emphasis is often placed upon public resistance to donation, and rather too little upon the public’s generosity” (Richardson 1996:91). In media stories, emphasis will certainly be given to the number of people waiting for transplant operations, or the number who have died without one, rather than the number of lives which have been saved. A report in the *Daily Express* (21.2.98), for example, disclosed that while “5,175 people in Britain need transplants, last year only 822 donors provided 2,800 organs.” Similarly, cases where relatives withhold consent for organ removal, “by far

the most significant cause of the non-use of otherwise suitable organs” (New et al. 1994:48), are foregrounded as “over 30 per cent of relatives” refusing (*Big Issue* 1997), instead of two out of three cases of agreement.

Quantitative surveys certainly suggest room for improvement in this area of organ availability. They regularly demonstrate a disparity between the number of people who report being in favour of organ donation and the number who actually carry donor cards (see Box 2). Health care professionals involved in transplantation, and indeed many people who promote organ donation as individuals or members of organisations, do believe that the number of organs available for transplantation would increase *if only* people could be made aware of the shortage of organs, *if only* everyone who was apparently willing to become a donor carried a donor card and *if only* people made that wish known to their family.

At this point, we realise that the potential donor’s family (legally, his or her next of kin) have a role to play, since they will be consulted about organ donation in the event of a relative being declared brain stem dead. A recent survey (MORI/UKTCA/BACCN 1995) supports the argument that telling one’s family about the wish to be a donor generally prompts their consent (see Box 3). In fact, the survey was conducted to ascertain the reasons relatives gave when “refusing a request for organ donation” (MORI/UKTCA/BACCN 1995:3). On this terminology, a telling point was put to me by the father of a donor. “Why,” he asked, “do reports say people ‘*refuse* to give consent’? Why can’t they say some families ‘*decline* donation’, or ‘*prefer* to keep the body intact’?”

BOX 2**Public Attitudes to Organ Donation**

Attitudes to being a donor

	OPCS	DoH	BKPA
In favour	70%	70%	72%
Against	13%	12%	18%
Don't know	17%	18%	10%

Donor card holder

	OPCS	DoH	BKPA
Yes, usually carry	19%	23%	25%
Yes, don't carry	8%	7%	7%
Not card holder	73%	67%	67%

OPCS Office of Population Censuses and Surveys, involved 2035 adults

DoH Dept. of Health (commissioned Research Surveys of Great Britain), involved 2000 adults

BKPA British Kidney Patient Association (commissioned Gallup), involved 1000 adults
(BKPA survey annual since 1988)

Tables are taken from 'A Question of Give and Take' -- reproduced by kind permission of King's Fund Publishing (New et al. 1994)

BOX 3**Reasons for Withholding Consent for Removal of Organs**

(From a Total of 515 Requests to Relatives)

24%	did not want surgery to the body
21%	knew the deceased had not wished to have organs removed
21%	felt deceased had suffered enough
19%	relatives divided over decision
18%	expressed uncertainty about the deceased's wishes

(Relatives may have offered more than one reason for refusal)

Survey conducted by MORI's Health Research Unit, among 328 participating ICUs in the UK.

Reproduced from 'Report of a two year study into the reasons for RELATIVES' REFUSAL of ORGAN DONATION' (1995:17) commissioned by the United Kingdom Transplant Co-ordinators Association (UKTCA) and the British Association of Critical Care Nurses (BACCN)

In the above report, in 18% of cases, relatives did not know the views of the deceased about organ donation while 19% of cases revealed that relatives were divided about what to do, which may also suggest the wishes of the deceased were unknown. One could argue that, if all those who died had carried donor cards, and made their wishes known, their families would have consented to organ removal. Promotional materials for organ donation repeatedly emphasise that no relative withholds consent where the deceased had explicitly stated the wish to become a donor in the event of his or her death. Of course, any argument about increased donor rates predicated upon such surveys assume that all those who were declared brain stem dead were in favour of being donors.

This belief is surely compounded by the ideal of altruism and the moral worth of saving lives, which we examined in Chapter Two. As Kahan (1996:137) has argued, “[b]ecause patient plight drives the entire transplant process, it seems inhumane to prohibit a person from any treatment that may restore life or health” especially when ‘all’ that restoration requires is something no longer needed by someone already dead. Underpinning this attitude towards organ transplantation is a biomedical model of the body as a machine; either it works, or it does not (Baudrillard 1973:159). Further, as a model of ‘everybody’, the advent of transplant technology means that, if one body cannot be repaired, its parts can be salvaged and used to repair other bodies. The resonance with ‘second hand’ car parts is striking (cf. Elkinton 1964, cited in Fox 1996:260; see also note 17, p. 269).

Paradoxically, the circumstances under which most solid organs currently become available for transplantation are extremely limited; the number of brain stem

deaths occurring in any one year is very low. A national audit of deaths in Intensive Care Units (ICUs) in England during 1989 and 1990, for example, estimated 13,000 deaths, of which 1,054 patients were confirmed brain stem dead with no general medical indications that their organs were not suitable for transplantation (Gore et al. 1992). Professionals working within the transplant programme, or conducting allied research, implicitly commodify organs when they apply commercial terminology to this disparity, frequently discussed as 'the gap between supply and demand'. Writing of the US transplant programme, Kahan (1996:139) proposed a strategy for restoring parity between "the extreme demand and limited supply " which should utilise the skills of individuals "familiar with supply and demand issues from the standpoints of economic and business theory." When such terminology is directly juxtaposed with discussions of the financial provisioning of the transplant programme (e.g. RCSE 1999), organs can be made to look even more like commodities; one might be forgiven for assuming that the expenditure of sufficient effort will ultimately 'produce the goods'.

As this section illustrates, though, the problem cannot be reduced to simple arithmetic, to be addressed through increasing production after the manner of commodities. At a basic level, though a total of seven major solid organs can be removed from those declared brain stem dead -- heart, 2 lungs, liver, 2 kidneys, pancreas -- not every potential donor will have suitably healthy organs, and preferences may have been stated about which organs could be removed (see Box 3). Similarly, the number of healthy organs removed need not directly reflect the number of recipients to benefit. The heart/lungs, for example, may be transplanted as a unit,

and repeat transplants to the same recipient do occur -- a kind of 'wastage' through the rejection of organs by their host bodies.²⁴ Improved clinical techniques are increasing the number of recipients who can benefit from the organs of a single donor; the liver and individual lungs can now be divided, with lobes going to different recipients. Nevertheless, while the waiting lists increase, the number of available organs does not.

Ironically, the disparity in Britain has much to do with efforts to prevent deaths among those who would have been potential donors. The RCSE (1999:19) report notes a drop in deaths due to intracerebral haemorrhage, from 5,609 in 1976 to 2,405 in 1996.²⁵ We can surmise that improvements in clinical care have contributed here. Figures produced by UKTSSA (1996:9) record a drop, from 31% in 1987 to 18% in 1996, in the number of donors who had been involved in road traffic accidents where traumatic head injuries are common (cf. New et al. 1994:14-15). Richardson (1996:89) witnessed the bald statement, made at a conference, that "the simplest way to produce more organs for transplant would be to repeal legislation requiring the use of seat belts in cars, crash helmets for motorcyclists, and speed limits on roads." The suggestion would not be taken seriously, but it does highlight in a graphic manner the current conflict at the crux of solid organ transplantation. To extend the lives of potential recipients the programme relies heavily on the deaths of other people, in circumstances which are themselves the subject of clinical or legal preventive measures.

²⁴ The need for repeat transplant operations would not be termed wastage, since the organs were being used in an effort to save or enhance lives.

²⁵ Among those aged 15 to 64.

Reviewing Alternative Sources for the Supply of Organs

A range of possibilities currently exists which could help redress the balance between the availability of organs and the number of people awaiting transplants. I outline these next. Contrary to implicit and explicit messages in promotional materials for organ donation, the disparity between the number of available organs and the number of potential recipients does not rest entirely upon individual preferences to decline the removal of organs. The content and impact of promotional campaigns, along with the legal framework of organ donation, are discussed more fully elsewhere.

Here I focus on what I shall broadly term ‘clinical’ possibilities which involve increasing the kinds of bodies from which organs could be removed. The picture is drawn with a rather broad brush, inadequate to the finer clinical and organisational details of ‘optimal use’ in, for example, the RCSE (1999) report, but sufficient to my purposes. These are to demonstrate a prevalent commercialised approach to ‘meeting the demand’ for organs, illustrated by the forced anonymity and presumed autonomy of bodies under examination as potential sites for the production of more organs, yet also to illustrate notions of connectivity reflected in ethical concerns about such body use. Finally, an appreciation of the other possibilities under consideration will assist in contextualising the pressures brought to bear upon living people to actively mark themselves as (future potential deceased) organ donors.

Clinical Measures to Increase the Availability of Organs

Clinical approaches to improving the supply of organs are not entirely separable from non-clinical issues. Increasing the number of brain stem death tests carried out in

hospitals, for example, would be a clinical practice carrying administrative and financial implications to do with available beds and staffing levels since potential donors require very careful and expensive clinical management, estimated at £2,000-£2,500 per 24 hours (RCSE 1999:20). Indeed, improving the management of potential donors to minimise organ damage has been recommended (RCSE 1999). These two measures appear least problematic ethically but, by comparison with others, seem to hold relatively little potential for a significant increase in organ numbers.

Wider development of non-heart-beating donation (RCSE 1999:2), and live donation (New et al. 1994:83; RCSE 1999:2) have greater numerical potential (RCSE 1999:20-21) and ethical questionability. Non-heart-beating donors would require minor but invasive surgery immediately after death, to insert a catheter for the purpose of cooling the kidneys whether or not they are subsequently removed.²⁶ Next of kin might not be present to give consent to organ removal; should the preparatory procedure be conducted in the hope of retrospective consent? (New et al. 1994:66).

Living donation, primarily of kidneys, could have a significant impact upon waiting lists since the vast majority of people are waiting for a kidney but, while living donors could give consent to organ removal, conducting major surgery on a healthy person for the benefit of someone else raises difficult issues for medical ethics ((New et al. 1994:66).²⁷ In these cases, biomedical ethics assumes it regulates the rights of autonomous, disembodied individuals in relation to biomedicine (Diprose 1995:202).

²⁶ Only the kidneys could be used from non-heart-beating donors. However the vast majority of those on the waiting lists require a kidney.

²⁷ Living donors could currently provide a single kidney, a lobe from the lung or liver, and a small bowel section. Healthy hearts removed from recipients of a heart/lung unit can also be transplanted.

“Taken to its logical conclusion, the notion of the autonomous self discourages the ideal of community and interdependence” (Diprose 1995:206); we can thus argue that the notion of autonomy is counterproductive with respect to tissue and organ donation.

Conversely, in the case of living donation, demonstrable autonomy appears to be required. Other arguments against live donors illustrate the tension provoked here, in the assumptions health care professionals hold about organ donation and the nature of relationships. One argument questions the voluntary nature of living related donation (Rudge 1997a:11-12, Rudge 1997b:46-48); according to the principle of autonomy, consent to donation should be ‘informed and freely given’, but people could feel obliged to offer an organ to a sick relative. Conversely, another argument proposes that, while living unrelated kidney donors could be used, they should have an established long term relationship with the potential recipient, to ensure the absence of financial incentives (RCSE 1999:26, 29). Presumably, the absence of ‘relatedness’ despite long term ‘relationship’ precludes the possibility of morally obligated giving.

Further evidence of implicit and interrelated assumptions are present in these objections; that organ donation must be free of obligation, that deceased donation lacks any form of coercion, that the absence of financial incentives can be ensured in any way, for example that a long term relationship between unrelated donors and recipients (often spouses) precludes any financially based recompense. The difficulties health care professionals envisage in keeping organ transactions free of these apparently undesirable elements are reflected in statistics. Though the RCSE

(1999:21) report noted “an increase of 32% in kidney transplants from live donors” in 1998, at 11% of all kidney transplants this figure has been compared unfavourably with 40% in Norway and 28% in the USA (National Transplant News, vol.15, p.1, 1998). Clearly, using the bodies of the anonymous dead is held to be far less problematic when informed by this ethical and moral framework, albeit precariously balanced upon the assumption of autonomy.

Two highly controversial options for increasing the supply of organs are elective ventilation and xenotransplantation. Elective (or interventional) ventilation would involve placing someone expected to die within 24 hours on mechanical ventilation (‘life support’) so that they suffered brain stem death, rather than cardiac death. This would be done solely to obtain organs, with no medical benefit to the patient concerned, rendering the bodies of the (nearly) dead even more like receptacles of spare parts for the living. New and his colleagues favoured pursuing this option (1994:83), reflected in the comment that “[i]t may not be long before actively managing death to save other lives is as ‘good’ and dignified a form of dying as any other” (1994:65).

Preliminary findings of the pilot study, presented at the BODY Convention in 1996, reported that no next of kin objected to the possibility of the procedure being carried out on patients who had met the clinical criteria. What the long term effects of such decisions might be on the families concerned could not, of course, be predicted. The hospital based study of this procedure was postponed when its legality was questioned; ethical concerns seem to be minimal (New et al. 1994:55-56, 63-66). Both the British Medical Association and the Conference of the Royal Colleges of

Surgeons approved the procedure though possible resistance to its actual introduction, by practising clinicians who would have to care for these potential organ donors, has been noted (Rudge 1997b:45-46). Thus we are reminded that ambiguities are apparent within the health care professions, particularly between those who care for potential donors, and those whose concern is for potential recipients.

Arguably the most radical development of all, xenotransplantation involves the genetic modification of animals to render their organs compatible with transplantation into the human body. Clinical trials using human recipients have been postponed until concerns about the cross-species transfer of diseases have been adequately researched. Numerically, xenotransplantation could potentially erase the waiting lists, assuming our health care system had the financial and human resources to respond to a limitless supply of organs. Yet, transplant professionals hold widely divergent views on the long-term efficacy of non-human organs (RCSE 1999:30).

Summary: The Commodification of Organs

Writing of the US transplant programme, Kahan (1996:139) remarked that it is constrained only by the availability of organs and the costs of transplantation. The RCSE (1999) report on Britain's transplant programme addresses shortcomings within the programme itself, which deter full utilisation of all available organs, not least the shortage of renal and liver transplant surgeons, as challenging as the shortage of donors according to its authors (RCSE 1999:8). In Britain, with its state funded health service, the extent to which financial costs are regarded as a legitimate constraint is a moot question. Few people interviewed in the present study seemed to

have given explicit thought to the financial implications of running a transplant programme with access to a substantially increased or even limitless supply of organs. On the other hand, the need for careful selection of potential recipients would be framed in terms of 'making the best use of a scarce resource'. One newspaper quoted the cost of a transplant operation at £60,000, reminding us that this 'free gift' must be accompanied by expensive biomedical expertise to cross over from the giver to the receiver (*Scotsman* 29.4.97b). With regard to kidney transplants, it will be emphasised that dialysis is the more expensive treatment; thus it could be argued that an unlimited supply of organs would actually reduce the transplant budget (*Daily Express* 6.4.00).

Several proposals for increasing the supply of organs have been examined. Different professional or academic groupings may favour and promote different approaches to increasing organ availability. Attitudes towards these approaches rest on subjective, taken-for-granted assumptions about the nature of giving, within established relationships, and as an anonymous act, rather than the "objective application of universal principles" of biomedical ethics (Diprose 1995:204), both of which are in any event predicted upon socially constructed images of bodies and individuals (Diprose 1995 *passim*).

In Chapter Two, I argued that organs are defined as gifts primarily because the notion of any monetary dimension to the transacting of human organs is abhorred. Yet a dominant metaphor in the discourse of shortage is that of the organ as commodity, framed within a commercial problem of supply and demand. Other language habits encountered during the present study -- in professional reports, academic literature, numerous interviews and informal conversations, revealed similar perceptions of

human organs, if not as objects to be bought and sold then certainly as “free-standing entities” (Strathern 1997:301).

Transplant professionals and recipients spoke in terms of the ‘new’ organ the recipient had received though, at best, organs are ‘second hand’. They are certainly not ‘spare’, another term I encountered, suggesting the surplus manufacture of, for example, machine parts (e.g. Longmore 1968; cf. Fox & Swazey 1974). I would argue that the use of such language reflects a wider tendency, certainly in Britain, to regard the body as a machine; this tendency has a long ideological and philosophical history in the West, well documented in academic literature. Mechanistic models of the body are intimately bound up with the development of Western biomedicine (Sawday 1995:28-32 esp.). In some instances the tendency is applauded (e.g. Miller 1978:9-11 esp.), in others it is criticised (e.g. Helman 1991: Ch. 6). Whatever the view, from this metaphor it is but a short step to regarding organs, consciously or unconsciously, as “replaceable parts,” a notion intimately bound up with modern capitalism and the commodity markets (Helman 1991:26). Yet replaceability suggests discardability, and here the commodity metaphor meshes with conservation rhetorics. As a potential donor in one promotional leaflet (1996) says, donation simply prevents organs from ‘going to waste’. The view clearly echoes the utilitarian connotations of organ transplantation, which recycles body parts, yet it also reinforces the gift’s altruism. ‘Why should I want anything back? It’s not as if I am giving away anything I need’. At the same time, human organs are gifts ‘beyond price’. No mere commodities, human organs can also be thought of as precious natural resources to be carefully husbanded.

Terms employed to describe how organs are obtained suggest similar perceptual shifting. The term 'harvesting' featured in academic literature (e.g. Chisholm 1988), though no health care professional used it in conversation with me. The term has an organic ring to it, suggesting the idea of a crop produced for use, but also provoking images of the 'Grim Reaper' and his scythe, mowing down those whose time has come to die (Richardson 1996:86-87). One co-ordinator told me the term harvesting had been taken up as a result of influence from the USA; television viewers of their imported hospital dramas will certainly be familiar with the term when organ donation has been featured as a storyline. 'Procurement' is the term widely used by health care professionals in the UK, resonating more closely with the commodity metaphor and its discourse of supply and demand. I found the term 'procurement co-ordinator' unpopular with donor families for the same reason they tended to dislike use of the uniform description 'transplant co-ordinator'. Both terms erase the presence of the organ donor. As if to further assist in the erasure of the donor's role, the procedure for removing the donor's organs is commonly described as 'retrieval', offering the image of something being *brought back* to its rightful owner, foregrounding the surgeon as the one who 'gives' the organ, and the one to whom gratitude is very strongly expressed by recipients. I have deliberately used the term 'removal' which reminds us that the organ is *taken from* someone else. Paradoxically, the term retrieval was used not only by health care professionals but also by recipients and donor families, which illustrates the extent to which we can unwittingly adopt the dominant linguistic habits employed in a particular context, my tendency to lapse into using 'transplant recipient' rather than 'organ recipient' being a

case in point. Again, the former term tends to erase the donor's role by laying emphasis on a technical procedure which has been made to stand for that which was transplanted, namely a human organ.

Chapter Four

In The Donor Realm: The Erosion of Voluntarism and the Erasure of Persons

This chapter treats the notion of voluntarism in organ donation, framed by an examination of the tension between its public profile and reports of actual participation. In their movement from the ordinariness of everyday life, into the trauma of a sudden bereavement, the donor families I interviewed felt they and their deceased children were being erased from the donation and transplantation process.

Section One focuses closely upon donor families, endeavouring to offer some sense of their disorienting, troubled and unlooked-for confrontation with the donation process. Among the families I interviewed personally, and the respondents to my questionnaire survey, commentaries on their negotiation through the donation process varied considerably. But in every case which came to my attention, the possibility of organ donation had been discussed within the family; at that time, no-one foresaw any difficulties. Retrospectively, relatives recalled being proud of their loved one's decision. Though they remain proud of that decision, actual involvement in the donation process has over time provoked deeply ambivalent feelings.

Section Two amplifies the erosion of voluntarism in the donation process. In Chapter One, some attention was given to elucidating the notion of choice as it manifests in promotional materials; this is now challenged. Many families feel they too have choice in the matter. They will have been approached by health care professionals for permission to remove organs according to their relative's wish: the

idea of coercion need not have occurred to them. Yet I am arguing that giving consent to organ removal is less voluntary than is generally supposed.

Section Three traces the gradual erasure of persons, donors and their family members, from the donation process, yet erasure necessarily entails 'something' left behind. To explain this feeling of erasure as it was reported to me, I draw on a simile from Battaglia's (1990:199) ethnography of mortuary practices on Sabarl Island, though it is not employed in the precise manner of Battaglia's informant. Erasing an organ donor resembles scrubbing a mark from floorboards; it leaves 'a bright spot'. There is the presence of an absence significant to the donor's family, but which others may not remark upon at all. Donor family members can feel a similar sense of being erased from the donation process, insofar as their participation is presumed to have stopped when they leave the donor realm or, perhaps, when they have received confirmation that their loved one's organs had been successfully transplanted.

I The Organ Donation Process

Insights into the actual donation process, presented here in a sequential format, mirror the process of becoming an organ recipient as it was recounted to me, and described in the next chapter. In both cases, the ‘process of becoming’ is inscribed quite literally through the practices of health care professionals upon the bodies of their patients. Donor families did not relate their participation in an ordered and sequential form; rather, this device allows me to foreground the presence and role of family members in the donation process, encountered by them as a sudden, bewildering, and emotionally devastating series of procedures enacted upon the docile bodies of their relatives, and over which they themselves had limited or no control.

The day it happened: The trauma of a sudden death

The majority of people who currently become deceased organ donors in the UK have usually experienced severe brain damage through either a direct injury to the head or spontaneous intracranial haemorrhaging. It is a traumatic situation for their families (Wright 1996); a serious accident or sudden, unexpected collapse, the rush to hospital, a barrage of technology -- ‘life support’, a tube through the mouth and down the throat, connecting the patient to a respirator which controls breathing.

Philip had told the hospital not to worry his parents. Rita and Conrad told me “we only found out when he was transferred to ICU.” Steve and Claire were away on holiday when Anne died; they travelled a whole day to get back home and to the hospital. “They’d told us Anne was in hospital and she had trouble breathing. Later,

we were told she went into respiratory arrest in the unit at 2 a.m. on the Tuesday.” In other words, she was already dead when the hospital traced them that morning.

Tom recalled finding his son, John, unconscious in his room one afternoon, the journey in the ambulance, Catherine, his wife, following in the car. John stopped breathing in the ambulance but was ‘stable’ by the time they reached the emergency department. A nursing sister introduced herself as the grief support nurse; “John is critically ill and may not live.” “She was rather clinical and detached,” Catherine said “but she recognised me as a former colleague, I was a nurse, and she seemed to become more friendly.” Confusion about the cause of John’s collapse meant a brain scan had to be done. John was subsequently moved to ICU.

Along with shock, bewilderment sets in. “What’s happening?” “Who can tell us?” “When will you know?” Steve and Claire had been overwhelmed by the confusion and lack of information. “When we got there, someone gave us brandy, sat us down, and said Anne had possibly had a brain haemorrhage.” “They couldn’t agree on a diagnosis.” “There was no post-mortem.”

The technology can be overwhelming, yet hypnotic; “something to focus on, something to do.” The physical condition of someone brain stem dead can exacerbate feelings of bewilderment for the bereaved family, since the deceased person is, to all appearances, ‘breathing’, still warm, with skin colour, and a heartbeat. Tom and Catherine found it “very difficult to take it in” that John was dead, though they understood that he was brain stem dead. He looked asleep, his body moved from time to time -- caused by spinal reflexes which continue after brain stem death.

Doing the Tests: Confirming Brain Stem Death and the Suitability of Donor Organs

Brain stem death is confirmed by a series of tests, carried out on two separate occasions and by doctors not involved in transplantation (Dept. of Health 1998:7). Sometimes relatives are asked if they wish to be there; none of the families I met were asked. A nurse described the tests to me as “brutal but necessary.” Health care professionals may, understandably, wish to avoid subjecting relatives to observation of the procedure. Other tests check potential donors are free of infections or diseases which could be transmitted to recipients of their organs (Dept. of Health 1998:16-17), and to assist in matching donor organs to recipients.

When donor family members spoke to me about “the tests,” it was related in the context of being asked about organ donation.

Then They Asked Us ...

The *Code of Practice* which guides health care professionals in the area of organ donation (Dept. of Health 1998) offers flexibility as to who approaches the potential donor’s family, and when. Time is a factor; the potential donor’s heart will stop beating within a few days, despite the respirator, and organs will cease to be ‘viable’. Perceptions of how much time relatives need varies considerably among health care professionals. For the families I met, the time given was ‘not enough’; they had all felt rushed, and ICU staff appeared uncomfortable in their presence.

Steve and Claire were approached “after the first tests” and asked to reach a decision “in the next few hours,” though two days lapsed before the second set was carried out. Anne had a donor card, but Claire needed to find it, “to be sure.” An

apparently little thing assumed a major significance. They went home to look and gave their decision next morning.

A senior consultant approached Tom before the tests were done on his son. "I knew they'd ask, as soon as they said John might die. I told him it was up to Catherine." She took up the story. "We knew John had a donor card; he'd talked about it but I needed to find it. I went home to look and they [staff from the ICU] phoned twice asking 'had I found it?'. Meantime, the consultant asked Tom, "Couldn't you just persuade your wife to agree?" Tom had been furious. The man had cried, re-living the events of John's death, but now he shook with anger at this recollection. Catherine said she had felt "as if there was already a recipient lined up." (Technically, of course, many potential recipients are 'lined up', on the waiting lists.)

The Donor Operation

If relatives consent to organ donation, the logistics of the removal operation are worked out and set in motion. It can take up to four hours, conducted by transplant surgeons, but performed in a theatre in the donor's hospital, so staff from that hospital can also be involved. One ICU nurse told me, "no-one likes that operation; I'm the only one who'll assist." Another nurse explained, "it's bad enough when a patient dies on the operating table but when one is brought in already dead, it's awful."

TU nurses also expressed a deep dislike of the operation. I met two who had gone to observe it as a matter of professional interest. One nurse particularly remembered the donor arriving in theatre with life support machinery maintaining oxygenation, and the body being placed in the "the crucifix position." The arms are

outstretched to allow full access to the torso, but the religious symbolism of the position was not lost on the nurse. The other nurse “thought the worst part was watching the heart being removed because it had to be deliberately stopped.” After removal, organs are packed in ice for transportation. Speed is essential. Heart/lung transplant operations must be performed within four hours, the liver within about sixteen hours; kidneys will ‘remain viable’ for forty-eight hours.

Afterwards: Post Operative Care

After the removal operation, the donor’s body is ‘restored’. This is particularly important, I was told, if relatives ask to view the body; they can be worried about what it will look like. Staff tended to believe ‘viewing’ left a more peaceful memory for the family. The donor families I got to know however had mixed views on this. Tom and Catherine had stayed with John until he was taken to the operating theatre, but “we weren’t asked about seeing him afterwards.” They wonder if it may have helped them. Steve and Claire were asked, but felt they had said their goodbyes to Anne in ICU, reasoning that “what was left [after the operation] wouldn’t be our girl,” which does not mean families are unconcerned about how their relative’s body is treated. As we saw in Chapter Three that is a source of much controversy.

Donor Family Support

One of the fundamental problems for donor families is that they are not hospital patients, not even out-patients. The donor was the patient; he or she is now dead. When the donor’s body is officially released to the family, they leave the donor realm

and any further communication is at the discretion of health care professionals. There is no formal, structured aftercare regime or regular out-patient visit for donor families to mirror that of organ recipients. ICU staff told me they tended not to maintain contact with the bereaved families of deceased patients, whether or not they became organ donors, mainly through a dislike of invading the family's grief. One nurse said she would like to attend the funerals of all the patients who died in her unit, but felt it would be an intrusion. I also encountered the view that contact with donor families is the responsibility of co-ordinators, the picture presented in promotional materials and acknowledged in the *Code of Practice* (Dept. of Health 1998).

Most of the co-ordinators I interviewed personally, or contacted by telephone or letter, did aim to send a donor's next of kin basic details of how their relative's organs were used; usually this included the age and/or sex of recipients. In a few cases, a structured follow up system was in place, and two areas I know of had established donor family support groups. But my research found marked disparities, between donor co-ordinators, and among the staff in any one transplant unit, in the extent of ongoing contact with donor families or supplying information about the progress of recipients who benefited from their act of donation. Sadly, I found that this lack of communication both arose from, and lead to, misunderstandings which left donor families feeling "used and discarded" as Catherine put it during one of our telephone conversations.

II The Erasure of Persons in the Performance of Organ Donation

Very few studies have been conducted, to date, with the families of potential or actual organ donors about their participation in this process; those which have tend towards finding ways to increase the number of families who agree to the removal of a relative's organs (e.g. Bartucci and Seller 1986). Implicitly or explicitly, potential organ recipients are the centre of interest in such research, not the bereaved families. A further tendency of such studies is to rely on reports from health care professionals about comments made to them by donor and non-donor families at the time of their relative's death or very soon after (e.g. MORI/UKTCA/BACCN 1995). Both tendencies erase donor families, limiting opportunities for understanding how they interpret their participation in the donation process, and what they regard as their needs, over a time period which takes adequate account of the long term effects of bereavement, and in a manner which acknowledges that, for the families themselves, participation in the donation process begins before their relative is admitted to hospital and continues for the remainder of their lives.

During the present study, I encountered a plethora of conflicting views about organ donation which, broadly speaking, can be divided into three levels. First, there is a public profile to organ donation, carrying certain messages which interconnect with highly valued moral ideals reported to be held by large numbers of the population in Britain. Next, the organisation and administration of the transplant programme involves rules or practices which belie the public profile of organ donation. I am arguing that this tension arises, certainly in part, from the third level -- behaviour in the actual performance of organ donation. We have seen that health care professionals

occupy a certain positionality in relation to the 'broken bodies' which call forth their attention (above, p. 114). Daily participation in the lives and deaths of their patients influences their perceptions in a myriad of ways, perceptions which then influence the public performance of organ donation. What I emphasise here is that assumptions about bereaved people in general and donor families in particular, embedded within the performance of donation, do not always accord with the perceptions of donor families themselves, increasing their sense of abandonment, and the perception that they and their deceased relatives are being erased from the donation process.

Erasing persons through inappropriate responses to bereavement

"A single person is missing for you, and the whole world is empty. But one no longer has the right to say so out loud" (Aries 1974:92).

There is a widespread view among academics who study death and bereavement that people at the turn of the twentieth- to twentyfirst-century Britain can no longer cope with death; an analytical conclusion generalised to the point of banality. The literature on the subject is vast (e.g. Simpson 1987) and a critical analysis would provide in itself sufficient material for a thesis. From my own research I wish to emphasise that all the bereaved people I met, or communicated with by telephone and letter, were 'coping' with a death in so far as they managed to continue their daily lives, in employment and in caring for their families and homes. What they could not necessarily cope with was other people's responses to their bereavement.

Avoidance

Avoidance was a common response among health care professionals. In one case, the serious grief of donor families was constantly emphasised by a co-ordinator, to justify refusing me any access to them through her office. Similar concern was demonstrated by the members of one REC against whose rejection of my research application I had lodged an appeal. At the appeal interview, some of the members were visibly horrified at the thought of my contacting bereaved people “when we have no idea what has been happening to them since their relative died.” Paradoxically, that was the very reason why I wished to talk to the families of organ donors -- to get their views on how they were managing their somewhat unique situations.

Those who do make the effort to speak to bereaved people may avoid mentioning the person who died. Donor relatives have told me it is as if the deceased person never existed at all. It can be worse when judgements are offered -- ‘shouldn’t you be getting over this by now?’ Michelle’s son said as much when he told her not to come back to visit her grandchildren until she had “cheered up.” Her grief has been intensified as a result.²⁸ A more subtle form of judgement is displayed, albeit unintentionally, when people try to disconnect the donation event from its wider context, and argue that any anger or pain felt by donor families is ‘just part of bereavement’, rather than having anything to do with the organ donation itself. The unspoken assumption is that one cannot feel anything but comfort from donation. Finally, platitudes are offered, though this is easier in some cases than in others, as Hockey noted (1990:37). When old people die, they’ve ‘had a good innings’. The

²⁸ I do not overlook the possibility that Michelle’s son’s attitude reflects his own unresolved bereavement issues.

deaths of young people are 'tragic', 'untimely', 'needless', sentiments reflected in public discourses about those who die waiting for a transplant, which may help to explain why efforts to comfort donor families can focus on organ recipients.

Displacing grief

Catherine told me how she had visited her son's dentist, with whom John had had an appointment on the day he died. It was some weeks after John's death and she just needed to know he had been all right then. The senior dentist, instead of talking about John, focused on the fact that he had become an organ donor, and remarked on the comfort this must be, to think of the people whose lives he had saved. Catherine just said, "no it isn't." Retelling the story to me, Tom said he did not care how many lives had been saved; he just wanted John back. We should not forget that donor families would have preferred not to be in the position of giving life to others. They would have preferred that their relative go on living, just as the families of potential recipients want their loved one to go on living. In the course of my research, I have learned that this is not an easy gift to give, and does not confer unequivocal comfort upon donor families.

While organ donation brings life to recipients (who are not without their own problems), the gift is solicited at a time of bereavement, often following a sudden and unexpected death. I have learned that a family's involvement in the donation process centres on the broken body of a 'significant other', which has called forth their care and attention, in a manner diverging dramatically from the public performance of organ donation, predicated on disembodied, autonomous individuals. A sense of being

erased from the donation process can be therefore be compounded by interactions with health care professionals, both at the time of a relative's death, and in any subsequent contact.

Conducting the conduct of donor families

Catherine and Tom were very distressed by the behaviour of staff in the unit where John died. The casualty department where John was first taken had a grief support nurse but the ICU had nothing of that sort. I suggested that health care professionals were in the business of saving lives, and found it difficult to cope with a patient's death. Tom picked up on the word 'business'. "Yes, it is a business," he said, "with no time to care. Business is my territory [that is his line of work] and in that environment, people are not trained to deal with failure. Only success counts!" He used to admire health care professionals and wonder how they did such difficult jobs. Now, "I'm very cynical about it all."

Steve and Claire also felt they were not being well treated, or given clear information; for example, the time of the removal operation was changed twice. The grief of this couple has been exacerbated in a number of ways. They were not with their daughter when she died; Claire was especially worried that Anne might have been in pain. When we met, nine years after Anne's death, they still did not know the cause, and they felt health care professionals were 'closing ranks' to prevent them from obtaining information they regarded as vital for their peace of mind. Lastly, as Steve said, "You expect to bury your parents, never your child."

The families I met were unhappy with the lack of support they received after the donation event, beyond the basic 'information letter' from donor co-ordinators. Co-ordinators have told me they always impress on donor families to get in touch if they need anything. As one put it, "I'm not psychic. Relatives have to tell me if there is a problem." Not all co-ordinators appear to encourage such contact and, if they do, donor relatives may not want to be a bother. Irene said as much, when she was explaining how she had initially declined to receive any information about recipients when her late husband became a donor. Six months later, she had changed her mind, and was very curious about them. I asked her what she had done to investigate. "Nothing" she replied. "I felt it was too late and I would just be a nuisance to the co-ordinator."

Steve and Claire had had experience of three different co-ordinators when we met. Four weeks after Anne's death they received a letter from the first, to say how many people had received transplants, but no other contact until a new co-ordinator took over a few years later. She was much better, they told me, keeping in regular contact with updates on the progress of recipients, and initiating an annual memorial service for all the donors in her area. The third one had been "no good at all."

Tom and Catherine derived little comfort from becoming a donor family, because it is woven into what they perceive as unsupportive treatment of their grief, extending into a lack of contact with the co-ordinator. They also received the information letter after John's death, with brief details of recipients; enclosed was an anonymous letter from someone who did not receive an organ from John -- a sort of

generalised reciprocity, sometimes employed by co-ordinators. “That” said Catherine “was it.”²⁹

²⁹ However, a few days after John’s death, John Evans of BODY telephoned ‘out of the blue’, at the request of the co-ordinator, to offer support, which he and his wife give unstintingly.

III From Voluntarism to Coercion in the Donation Process

During my study, I frequently encountered the view that bodies, after death, are resources which should be used to save other lives. Non-utilisation of this precious bio-material, which would otherwise 'go to waste', leads to unacceptable social costs - that is the needless deaths of those who could be given transplanted organs. Juxtaposing these perceptions of the bodies of potential organ donors and potential recipients, with Lock's (1996b) eloquent remarks about 'the heroics of saving lives' and 'the moral worth of giving', the voluntary nature of organ donation presents as self-evident.

The presumption of free choice in deceased donation, as opposed to coerced giving in living donation, has already been noted (above pp. 128-9); living donation is not favoured because obligation is present when the potential donor and recipient are known to each other (cf. Rudge 1997a:11-12). Contrastively, the women Konrad (1999) studied, who donate their ova, seemed to be exercising choice, as did the respondents in Titmuss's (1970) study of blood donation. In both cases, anonymity is a key feature yet this should not lead us to assume that deceased organ donation is devoid of coercion because it is anonymous. Within the donation process, anonymity has its degrees, which render the transacting of human organs less voluntary than the rhetoric of donation leads us to believe.

Compounding the situation, a study of general media and official promotional materials further undermines organ donation's presumed voluntarism, the public call for organs taking a highly emotive and publicly visible form in contrast with that for reproductive tissue and blood. When we also take into account the fact that an actual

donor's body is that of a loved one, the notion of choice is further undermined. Lastly, the pressures upon transplant professionals to save the lives of their patients enables us to trace a flow, if not of coercion, then certainly of strong elicitation, from the realm of the recipient to the realm of the donor and beyond, into the public domain. In this section, that flow is traced 'upstream', so to speak, beginning with the public performance of organ donation and moving towards the individual persons who receive the substance of others.

The rhetoric of choice

Organ transplantation is conducted on a global basis, but the processes by which organs can be obtained and used are constrained by legal and cultural practices, as Lock (1996b) has demonstrated in her comparison of the US and Japan. Alnaes (personal communication) makes a similar point in relation to Norway. While it could be argued that legal regulations are an expression of cultural conventions, it may be more appropriate to say that different cultural conventions influence legal and clinical codes, as evidenced by disparities, in Britain, between the law which governs obtaining and using organs, and the procedures adopted by health care professionals. Chapter One gave a brief outline of legal procedures for recording one's wish to be an organ donor. This chapter has introduced administrative practices informed by medical ethics. Maintaining that separation hereafter has limited value; I largely address them together.

Current British law governing the mode of obtaining human organs for transplantation offers the jural individual more freedom of choice than other countries;

in the USA, for example, doctors can be legally obligated to approach families in all cases of potential donation, while in Austria organs can be arbitrarily removed from the bodies of the dead. Britain operates an 'opt-in' system of *required consent*. 'Choice' is presumed to be a fundamental aspect; one chooses to be a donor, chooses the method of formal record, chooses which organs may be removed. Donor families often emphasise the generosity of their loved one who chose to think about organ donation and make the effort to act on their decision.

Promotional pressures

In order to 'make a choice' about organ donation, one needs to be aware of its possibility. Over the course of my study, a range of official promotional materials and other publicity came to my attention; I conducted no systematic survey, but rather sought to observe the form and manner by which information about organ donation might be encountered by members of the public. Television documentaries, for example, were prominent during annual National Transplant Weeks. While writing this chapter of my thesis, the media featured a prominent coverage of one set of parents appealing publicly and successfully for a heart for their dying child.

At such times, it would be difficult for people who watch a reasonable amount of television or buy a daily newspaper not to be convinced of a perceived shortage of organs. Listening to comments from colleagues, friends and family members, one could also surmise that the stories of people, especially children, waiting for transplants are emotionally provocative. Yet, as interpretations of statistical surveys report (see Chapter 3), 'not enough' people take steps to register as potential organ

donors and 'not enough' families agree to the removal of a deceased relative's organs.

Recalling Richardson's (1996:88) comments on "the constant refrain of shortage" in public and academic discourses about organs for transplantation, she further remarked that "too much emphasis is often placed upon public resistance to donation, and rather too little upon the public's generosity" (1996:91). In the media, emphasis will be given to the number of people awaiting transplants, or the number who have died without one, rather than the number of lives which have been saved. The *Daily Express* (21.2.98) disclosed that while "5,175 people in Britain need transplants, last year only 822 donors provided 2,800 organs." Similarly, cases where relatives withhold consent for organ removal are foregrounded as "over 30 per cent of relatives" refusing (*Big Issue in Scotland* No. 136, 1997), instead of two out of three cases of agreement.

Consequently, this gift has to be elicited and in official promotional materials an increasingly strident message can be identified. In two promotional leaflets, produced in 1994 and 1996, found at my GP's surgery and a third, produced in 1998, acquired at a BODY Convention (Plates 1-6), textual content and emphasis changed from general details about the donation process, to prominent slogans of 'the gift', to forceful facts about transplant waiting lists. The third leaflet tells us that many people will die without a transplant, and -- 'it could be you':

You are much more likely to need a transplant than to become a donor. If you are prepared to consider accepting a transplant for yourself or your family, it seems only fair to play your part by being willing to be a donor.

The point is powerful and, on the face of it, seems perfectly just. If we are prepared to take, we should be prepared to give, as a matter of social responsibility. When the point is linked with the other facts and figures of transplantation, and the direct personal equation between giving and receiving, the voluntary nature of donation is overlaid with a strong persuasive quality.

Taking a step further, the promotional poster for National Transplant Week (20-26 July 1998) featured a photograph of nine year old multi-organ donor Lucy Maxfield, with the caption

“In September 1997 Lucy saved the lives of five people ... by accident.”

National Transplant News (1998:2) noted that “[n]ever before had such a powerful image been used to convey a simple message, and Lucy’s touching story reached the hearts of millions ... [to help] create an awareness of the terrible shortage of organs.”

That ‘terrible shortage’ can lead to an explicitly coercive approach being aired in the public media; in one case, people who do not carry donor cards are accused of selfishness (*Daily Express* 3.9.96); in another, those who refuse permission for the removal of organs from their relatives are accused of ignorance or superstition (*Big Issue in Scotland* No. 136, 1997); in a third, the girlfriend of a young man who died before an organ became available said doctors should just remove organs from any suitable donor, without reference to his or her family.³⁰

An equally controversial view of acceding to a family’s request featured when I took part in a radio discussion about an incidence of ‘conditional donation’, where parents had specified that their son’s organs should only be given to white people

³⁰ This was sent to me by Rita. I have been unable to trace the reference.

(BBC Radio 4, 'P.M.' programme, 7.7.99; cf. Dept. of Health 2000). Rather than using the incident to justify excluding families from the decision about organ removal, I suggested that the offer should be politely declined. Also on the programme was Mrs Elizabeth Ward, President of the British Kidney Patients Association, who held that my suggestion was condemning potential recipients to death. She preferred that the organs were taken and used for white people, since any life saved was an end which justified the means. The Department of Health's (2000:1-2) inquiry Panel disagreed, indicating that neither donors nor their families should be permitted to choose categories of potential recipients.

The obligation to invite

From my discussion of law versus medical ethics in the matter of organ donation, it might be assumed that health care professionals have considerable choice about approaching families on the question of organ removal. Health care professionals may themselves be reluctant to regard their deceased patients as potential donors and prefer not to approach the relatives about organ and tissue removal, an issue given some prominence within the transplant programme. Speakers at the BODY Conventions I attended addressed this professional reluctance. In one magazine article, it was linked with the idea that families derive comfort from choosing to allow organ removal. "By not asking, we make that choice for them" (Sainsbury's *The Magazine*, Sept. 1995, p.64). In another article (*Big Issue in Scotland*, No. 136, 1997, p.8), co-ordinators proposed that "this is where [we] step in" to ease the burden for ICU staff. Directly addressing nurses, and placing the reluctance to ask

within the frame of Mauss's (1990) theory of gift exchange, Sque and Payne (1994) have argued that health care professionals, particularly nurses, had an 'obligation to invite' families to permit organ removal from their deceased relatives.

A leaflet produced by the Heart Valve Bank, targeting health care professionals, illustrates the obligation to invite.³¹ The force of the message suggests it is the duty of health care professionals to save lives by obtaining this gift. Highlighting a serious shortage of heart valves for transplantation into babies and children, a quote on the inside page in large bold type states, "Unless they have this transplant they WILL die..." (original emphasis). The leaflet also illustrates the advantages gained from donation, using photographs of 'Ryan', as a very sick baby, a healthy 2 year old heart valve recipient and a lively little brother with his sister, 'Laura', who produced the leaflet's graphics.

Concurrently the coercive nature of the leaflet's dominant message, and any worries health care professionals may have about approaching bereaved relatives, are offset by an emphasis on the voluntary and strong wishes of donors themselves, expressed directly by their bereaved spouses, as well as by the comfort those spouses have derived from the generosity of the gift. Significantly, the leaflet also carries photos of donors and their partners; thus donors, recipients and the relatives of both are clearly identifiable as such -- something I had not found in any of the publicly available promotional materials which came to light during my research. In the public domain, the anonymity of donors in particular had been emphasised as a desirable

³¹ No identifying reference. Although heart valve is tissue, the approach adopted when addressing health care professionals is illuminating.

feature of donation and strictly maintained -- until recently, as we saw above in the case of Lucy Maxfield.

Choice and familial obligation

Under British law, bodies are not regarded as property. They cannot be owned, and therefore they cannot be disposed of in the same manner as property in a formal will. Rather, the bodies of the dead have 'persons in lawful possession', depending on circumstances. According to the Human Tissue Act 1961, operating on the basis of *required request*, where someone has died under the appropriate circumstances and is found to be carrying a donor card or listed on the donor register, the designated representative of a Health Authority is empowered to authorise removal of organs. Where the potential donor had not registered in any formal way, the designated representative must be confident that neither the deceased nor any surviving next of kin expressed objections to organ removal (Dept. of Health 1998:13). At the same time -- and this is where a set of cultural conventions generated within 'the clinic' can be seen to conflict with those which influence the enactment of laws -- the *Code of Conduct* guiding health care professionals in clinical and administrative aspects of obtaining organs advises health care professionals to make every effort to contact and consult the deceased's family, irrespective of the deceased's identifiable status as an organ donor (Dept. of Health 1998:10, 13).

In all the conversations I had with health care professionals and donor families, it was clear that the *Code of Conduct*, rather than the law, was followed. No health care professional I met was happy with the idea of removing someone's organs

without consulting family members, because of the sensitive emotional state of those relatives and the need to avoid actions which might exacerbate their distress.³² One co-ordinator told me that the wishes of relatives must be respected so as to assist their bereavement process. The point is emphasised in promotional materials which state that, legally, the approval of relatives is not required, but it is nonetheless always requested ... nowadays at least.

Presenting a paper at a BODY Convention I attended, a well known surgeon remarked that in the early days of transplantation organs were removed from deceased patients without consulting relatives, some of whom complained, so the procedures were altered. This surgeon's remark was a casual anecdote and no more information was given; at the time, his comment seemed to fit with other views I had heard expressed about consultation with a potential donor's family. Organs must be seen to be freely given, under the control of the donor, before death, or the relatives after the donor dies.

We must remember, of course, that 'freely given' is also taken to mean the absence of conditional giving (Dept. of Health 2000:1, Point 1.3). The Department of Health's investigation into an incidence of conditional organ donation illustrates official recognition that control should not be entirely in the hands of the donor or donor's family. Recalling the stories told to me, we can question whether families in this predicament have any sense of control at all. Traumatized by the sudden deaths of their children, bewildered by a lack of information, feeling pressured to agree to organ

³² However, see my comments about the BMA and *presumed consent* in Chapter 6.

removal, and rushed into a decision, suggests a marked absence of control which has left the families I interviewed angry and in despair.

Similarly, if “there are no recorded cases of relatives refusing donation in the face of a donor card” (New et al. 1994:48), there is room to question the extent to which a donor’s family actually has any ‘free choice’ in the matter. The point is by no means insignificant; doing what their loved one would have wanted is a paramount concern for many bereaved families.³³ Arguably, they have no choice; acceding to their loved one’s wishes about organ donation is a matter of obligation. Tom expressed this poignantly when he remarked that John had made the decision about becoming an organ donor while he and Catherine were left with the consequences. For a number of donor families who participated in my research, those consequences were not as comforting as they had imagined, and there were limited opportunities for expressing dissatisfaction.

Another factor destabilising the rhetoric of choice in organ donation was mentioned by a few nurses and co-ordinators, who said that the availability of organs was susceptible to media influence; one “bad story,” for example, about removing organs from a deceased person whose family had not been asked, could directly affect subsequent donor numbers. In my early conversations with donor families, they acknowledged this delicate issue and expressed reluctance to speak publicly about their poor treatment ‘in case it put people off organ donation’. In effect, these families were coerced into supporting the public performance of organ donation by suppressing their own less comfortable stories, thus contributing to their own erasure

³³ Certainly among all the bereaved people I have had conversations with, not only donor families (cf. Howarth 1996:123)

from the process. Gaining a measure of strength as they have moved through bereavement, and feeling that organ donors and their families should not be so readily cast aside “after the event,” Catherine and Rita have attempted their own resistance to the public performance of organ donation.

Resisting Coercion and Erasure

In February 1999, at my invitation, Catherine agreed to speak of her situation on a radio programme (BBC Radio 4, *Woman's Hour*, 5.2.99), which was to have focused on the participation of families in decisions about the removal of a relative's organs, and their need for support after the donation event. The inclusion of a senior transplant professional in the discussion shifted the spotlight to ‘the refrain of shortage’ (Richardson 1996), particularly of kidneys, to “the failure of [donor card] campaigns,” “a general degree of apathy” towards carrying donor cards, and to “families who block [one's] stated wish” to donate organs, concluding with waiting list numbers. This had really angered Catherine, who later said she did not think she could do anything like that again.

Rita and Conrad were originally very dubious about drawing attention to their situation. Conrad remarked, “it wouldn't go down very well with the medical profession.” When they presented £1,200 to the ICU where Philip had died, the hospital press office brought in a local reporter whose paper “did a lovely piece” about the humidifier for a life support machine, bought with the money collected, as a memorial to Philip and mark of gratitude to the ICU staff who had tried to save his life. Unfortunately, delays in purchasing the equipment, then administrative pressures

in the hospital press office, meant it had taken two years for this to happen, with no explanations to Rita and Conrad about the delay. They were less happy with the article in the hospital's own paper which, the couple said, "hijacked" the story and used it to promote organ donor cards. "So it wasn't really about Philip at all."

Three years later, Rita was sufficiently upset by a newspaper item about an organ recipient, in which there was no mention of the donor or family, that she wrote a letter to the newspaper, "never expecting it to be published." But it did appear (Plate 7).

Although these seem small steps to take, I have a vicarious sense of their magnitude for Rita and Catherine. Rita has since been contacted by her area's co-ordinator to say that, as a result of her experiences of the donation process, much hard work is being done to improve the quality of support for donor families. So, as Rita remarked, "we have tried, and accomplished something between us."

Summary

This chapter has addressed the attitude of donor families that they and the donor are erased from the donation and transplantation process, and we have examined some of the mechanisms by which this occurs, anonymity being a key feature.

It has been demonstrated that the anonymity of organ donors and their families is variable and manipulable. Most importantly, organ donors were, and in significant ways will always be, implicated in the lives of friends and family members who survive them (see Plates 12-14). Promotional material might guarantee anonymity in a generalised form as a valuable feature of the organ donation and transplantation

process, but as Lucy Maxfield's poster demonstrates, the apparently desperate lack of organs for transplantation prompted the transplant community to abandon donor anonymity in favour of a 'powerful image' designed to provoke intense emotional responses towards those who need transplants. Reversing what people in Britain have come to understand as the 'natural order' -- adults protecting children, and death taking us in old age -- we are confronted by a young child with the generosity and forethought to carry a donor card, and who thus saved the lives of two children and three adults when she herself was killed in a road accident.

Such imagery undermines the supposed voluntarism of organ donation. We may 'have a choice' when Britain's legislative position is contrasted with, for example, Austria, and there are elements of free choice in the matter of recording one's willingness to become an organ donor. Nevertheless, we have seen that a plethora of promotional materials seek to encourage registration; the act of giving has to be nurtured. In form and content, these materials can display strongly persuasive tactics, openly acknowledged in a study designed to increase the number of donor card carriers, albeit in the USA (Skumanich & Kintsfather 1996). Persuasion merges with coercion when those who do not carry donor cards, or do not consent to the removal of a deceased relative's organs, are subjected to moral condemnation in the media.

Despite an obvious concern among health care professionals to show sensitivity, the families I met felt strongly pressured by hospital staff to agree to organ removal. Where families appear to be willingly following their loved one's wishes about organ removal, any notion of 'freedom of choice' can be eroded by the

emotional aftermath of that decision. Contrary to the perspective that human organs are (always) anonymous, detached, commodified objects, not implicated in the identity of the donor, for the families in this research the now transplanted organs of their children were far from anonymous and detached. How and where they had been used was enormously important information.

This leads me to introduce the next chapter where it will be seen that the identity of organ donors travels with their organs, into the realm of the recipient. There is a further way in which organs have to be elicited, relating directly to their corporeal form. Human organs cannot simply be 'given', handed over in the manner of 'presents' passed directly between two known people. They must be physically cut out of the giver's body by a surgeon. While the 'retrieval team' is at the donor's hospital, conducting the removal operation, a particular recipient is already being prepared to receive an organ from a particular donor. In their turn, then, surgeons are 'coerced' into acquiring organs for their patients, who would otherwise die. Thus, the needs of potential recipients drive the process of alienation to the extremes depicted in this chapter, where anonymous organs are to be arbitrarily removed from anonymous bodies with no thought for the bereaved families. But as Chapter Five will show, actual recipients can have very different attitudes towards their transplanted organs, the persons from whose bodies they were removed, and the families left bereaved.

Giving thanks where it's due

I HOPE the girl who received an organ transplant recently recovers. Her father was very thankful and thoughtful regarding the donor. Often they are never mentioned. Our son was a multi-organ donor four years ago and was able to help seven people. We received one letter of thanks. To carry a card is a very unselfish act. The family, left behind, have all the trauma of carrying out the donor's wishes, along with the grieving.

Kidney recipient Janet Bennett said that it was "better than winning the lottery" (Express, April 12) – there was no mention in the report that someone had to carry out the wishes of a donor in their family, or be asked if they would agree to donate organs. I hope more people will remember that someone had to die before there could be a transplant.

*Rita Jackson,
Morecambe, Lancashire*

Rita's letter in "The Daily Express"; 15.04.00.

Dear Friends,

I hear that you have been enquiring about my health, following my transplant operation in March. I'm glad to say I'm progressing very well - a few minor setbacks here and there, but I'm getting stronger every day.

For two years before the transplant I lived, ate and slept in an armchair, on oxygen eighteen hours a day and I could feel myself gradually slipping away. Perhaps, then, you can realise the immense gratitude that I, my wife and daughter and my family and friends feel towards my donor and his family for the new life I have been given.

Last Saturday, for example, my wife and I visited Dunham Massey. We had a meal in the upstairs restaurant (for the last four years I haven't been able to climb stairs) and then toured the old house. It was a lovely afternoon and I walked, perhaps half a mile, and drove eighty miles - none of which I could do prior to the transplant.

So, thank you for my life. I only hope that the joy I've been given compensates in some small way for your own grievous loss.

Yours truly,

A grateful recipient.

An example of a letter from a recipient to his donor's family

Chapter Five

The (Dis)Placement Of Connectivity: Organ Recipients And The Management Of Guilt And Gratitude

This chapter focuses on people who have received the 'gift of life'. The social and emotional ramifications of receiving an organ extend far beyond the act of donation itself, materially influencing the lives of organ recipients. As shall become apparent, feelings of guilt and gratitude reported by organ recipients undermine the voluntarism and anonymity of organ donation in the recipient realm.

The process of becoming an organ recipient is described in Section One. Awaited with eagerness, it may take considerably longer than becoming a donor, and is recognised to extend beyond the immediate transplantation event; in actual practice, organ recipients are acknowledged to remain recipients for the rest of their life and a support service is available for them.

Section Two returns to the theme of anonymity. Here we see a reversal of the anonymising process described in Chapter Three. Human organs personify their donors, and recipients may feel compelled to imagine an identity in the absence of concrete information. At the same time, recipients do report bodily and psychological changes to themselves, as persons, often expressed as feeling like 'a different person' or 'a new person'. These changes, I am arguing, derive from recipients' participation in the tangible and intangible substance of their donor.

Section Three addresses the most controversial issue to arise during my research -- that of direct communication between recipients and their donor family. The decision about writing may not be in the hands of recipients, though most

expressed the wish to do so. The issue of communication returns us to the donor realm, and to donor families, leading into my final chapter on the tension between autonomy and connectivity in the transplant programme.

I **Becoming an Organ Recipient**

Starkly contrasting with the sudden, unexpected and unwanted entrance of donors and their families to ICUs, for all the recipients I met referral to the transplant unit was the culmination of months, even years, of illness which they took considerable time to recount to me in a sequential narrative.³⁴ They had to be prompted to tell me what happened after their operation. My initial approach may have provoked this narrative sequencing. When we first met, they all asked “what do you want to know?” or “where will I start?” But given that they had been ill for a very long time, it was understandable that ‘how they got referred’ should illustrate the duration and seriousness of their illnesses, and that their stories ended with the operation which, so far as they were all concerned, “saved my life.”

Each recipient acknowledged the operation was, if not a culminating event, then certainly a watershed. Anthropologically speaking, it resembles the liminal zone in a rite of passage (Turner 1967; cf. van Gennep 1909). Recipients undergo a major change of status; in contrast to their life of ill health, the ones I met all seemed to feel they were awaking from the operation to ‘begin afresh’. Many recipients think of the day of their operation as a second birthday. With further prompting, they talked about the after-effects of their operation, and how they were managing to cope with the difficulties of a demanding aftercare regime.

³⁴ It is also possible that potential recipients become ill very quickly.

'I knew something was wrong': getting referred to the transplant unit

Potential recipients are referred to the transplant unit from other areas of health care. Keith's referring consultant "thought I was too old but my daughter insisted." All the recipients I met said they "just knew" something was very wrong. Helen's story is fairly illustrative. She knew she was dying. No-one had actually used the word 'dying', but eventually one houseman had taken her aside and said "there is no more we can do for you" -- then he mentioned the possibility of a transplant. Helen said she'd try anything. This was a lifeline and she "would have done anything to get onto the list."

The recipients I met all said they 'had no choice'; it was 'either a transplant ... or death'. Robert made the point eloquently, saying "I was never very keen on human organ transplants, never mind animal ones,³⁵ but all that changed when the consultant said 'you need a transplant'. When you are standing at the edge of the precipice, things look very different." Some recipients had expressed doubts, particularly about getting the chance 'at their age'. One man in his late 60s wondered if it was right that he should get a chance when younger people also needed transplants. Similarly, Mary said she got very upset when she heard about young people dying. "It doesn't seem fair when I got the chance," she said. However, neither of them seriously considered refusing a transplanted organ. In fact, a friend once asked Mary, when she was having a very bad day, depressed about the death of a neighbour's young husband, if she wished she had not had the operation. Her negative reply was emphatic.

³⁵ We had been discussing xenotransplantation, genetic engineering of pigs, to produce organs compatible with human bodies.

The Assessment

One endeavour on the part of transplant unit staff to control the disparity between the availability of organs and the number of people waiting for operations is through an assessment of patients.

For potential organ recipients, The Assessment (I always felt recipients were saying that with capital letters) has huge implications, since it can mean they are not accepted on to the waiting list.³⁶ TU staff told me many recipients have a “hard time of it,” after their operations, citing cases of “serious depressions” and “marriages breaking up.” “Living with a transplant” is demanding, I was told; physical and emotional progress difficult to predict. Senior staff want to assess ‘family support’ as well as a patient’s physical and psychological status. Spouses, especially, are expected to participate in The Assessment. Here, connectivity is unambiguously recognised and co-opted.

Several recipients I spoke to regarded the assessment as “an exam,” their only concern being how to pass it. Tony thought it was all to do with his behaviour, “like having the right table manners”; he was desperate to “do it right.” Robert regarded it like an interview. “You have to be on form.” Keith remembers the very first thing the surgeon said was “there’s no age limit, but I won’t put a good liver into a bad body.” When the surgeon said Keith would eventually become “like a vegetable” as a result of his illness, his wife said she would cope -- she was worried about the risks of a transplant, but Keith wanted to take the chance. Otherwise, he said, it would be “too much of a burden on her.”

³⁶ Unfortunately I was not able to ascertain how many people are rejected on an annual basis.

The Recipient Co-ordinator

Recipient co-ordinators, responsible for administrative aspects of transplantation, occupy a pivotal liaison role within this realm; usually meeting the recipients prior to assessment and taking an active role during assessment. Recipients told me the co-ordinators had especially asked for their thoughts about 'getting a transplant', discussed the operation's recovery period and described the aftercare regime. Co-ordinators are part of the unit team which reviews the suitability of people referred for assessment, though the transplant surgeon will make the final decision. Although the British Medical Association's position is that the judgement should be entirely clinical (*Scotsman* 29.4.97b), one senior nursing officer acknowledged to me that decisions usually involve subjective judgements about a potential recipient's background. Consequently, decisions can be rendered ambiguous (see New et al. 1994:79-80; cf. *Scotsman* 29.4.97a, 30.4.97). If people are accepted on to ~~the~~ waiting list, their 'official' entry into the recipient realm is formalised by presentation of a personal pager.

Waiting for The Call

Potential recipients constantly carry this pager, through which their unit will contact them when an organ has been located. The recipients I interviewed had waited from a few weeks to over a year. Maintaining some semblance of 'normal life' was important but difficult. Helen spent time making plans for her family, "in case I died." Other recipients talked about not telling their family everything, of wanting to protect them; conversely, they realised their family members wanted to protect -- perhaps

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Potential recipients constantly carry this pager, through which their unit will contact them when an organ has been located. The recipients I interviewed had waited from a few weeks to over a year. Maintaining some semblance of 'normal life' was important but difficult. Helen spent time making plans for her family, "in case I died." Other recipients talked about not telling their family everything, of wanting to protect them; conversely, they realised their family members wanted to protect -- perhaps

overprotect -- them, determined to keep them alive until an organ became available. Katy said people were worried about taking her out anywhere "probably in case I collapsed." Keith said his wife did everything for him. "She'd have drunk my tea if I'd let her!" he joked.

Exacerbating the situation, potential recipients do realise they are waiting for someone to die. Tony acknowledged using some "very black humour." Looking back, he is not happy about some of the things he said, but "I did it; it's how I coped." Marjory also knew she was waiting, hoping, for someone to die "so I could get my transplant ... and that's an awful thing to be doing."

Getting The Call

All the recipients I spoke to, with one exception, "got the call" at home, though one told me his pager had a habit of going off on its own accord, causing two false alarms on car journeys. Robert, a wonderful raconteur, related his rather fraught ambulance journey with gusto; first it arrived late, then it broke down on the motorway. However, "we got there!"

On arrival at the transplant unit, recipients are 'prepped' for their operation, before the exact suitability of the allocated organ is determined. While bodies can be viewed as containers of 'spare parts', the parts are by no means uniform. Internal organs vary in size and each is chemically unique. Relatively close matches do occur, but the complete suitability of any organ can only be determined once it is removed from the donor's body, and subjected to a final sequence of tests. Potential recipients must be sent home if the match is not suitable. Keith was sent home again the first

time he got the call; "It was the worst night of my life." He closed the door and the curtains, and "ate worms" -- a humorous reference to a Scottish children's rhyme. It was at this point he fully acknowledged, "I could die."

The Transplant Operation

The recipients I met all said their operations had 'gone smoothly'. Most of their narratives concentrated on the immediate post-operation period. Everyone spoke of how they felt an intense sense of euphoria and well-being when they regained consciousness. Helen said she felt "all glowing," as if it wasn't really her, she felt so different. Thomas was amazed at how free of pain he felt. Keith said he remembers waking up and asking "when's my operation?," while Tony woke up to discover a nurse cleaning his teeth.³⁷

Afterwards: the post-operative recovery period

Contrary to public perceptions, and indeed the notions of some of the recipients I met, a transplant does not restore full and immediate health. Though they all woke up from the operation with intense feelings of well-being, none of the recipients suggested that the recovery period was 'plain sailing'. There is physiotherapy, special diets, and learning to monitor intake of all the drugs which help recipients' bodies accept the organ. Some recipients were very ill for weeks, even months; others spoke of being 'up and about' in a matter of days. Some then stayed in a small flat on hospital

³⁷ Since the mouth is a primary entrance point for infections, oral hygiene is very important - see infections (p. 175).

premises for a few weeks. All organ recipients return as unit out-patients for regular check-ups.

Recipients spoke frankly about the discrepancy between their hopes and the reality of their recoveries. Michael showed me the booklet his unit had given him, and said staff really made sure he read it all, so there were "no surprises." So, nothing had surprised him? "Well, I really didn't believe it would take me so long to recover." Gary said he was determined to "beat the book," which suggested recipients could be back to work in three months. He would do it in less time than that -- he would be a model patient. Unfortunately, he never has recovered enough to return to paid employment, though he does voluntary work to keep himself occupied.

Most of the recipients I interviewed, and many questionnaire respondents, reported successful operations and good post-operative recovery periods. In the longer term, the actualities of living with a transplanted organ have developed a variegated complexion. Recipients' lives had certainly been extended beyond expectation. Elation and relief from the burden of imminent death showed in the humour with which they recounted their stories to me, in contrast with the stories told by donor families. Yet recipients also spoke of dramatic and not entirely welcome changes to their bodies and perceptions of 'themselves'. As I argue in the next section, these changes relate both to the presence of tangible, alien substance within their bodies, and also to the 'intangible substance' of personhood irretrievably entailed in the cross-bodily transfer of human organs. In other words, the ongoing process of a recipient's self-making implicates the 'present absence' of the organ donor and his or her family.

II Consuming Parts: From Anonymity to Personification

While organ donation is presented as anonymous, and organs can be made to resemble detached objects with no social identity, their alienability from their donors is curtailed for recipients. As I shall shortly demonstrate, the donor's death tends to focus a recipient's attention on a particular, if still anonymous, person. First, I wish to illustrate an organs's physical inalienability, the effects of which I locate in certain of the recipient's responses to the organ itself or, less directly, to the operation or drug regime which accompanies it.

Detachable yet inalienable

Human organs are literally detachable; they can be cut out of the body and stand as separate objects. But transplanted organs are 'alien' to recipients' bodies. To prevent a recipient's immune system rejecting the organ, large quantities of immunosuppressant drugs must be ingested every day, yet this exposes recipients to infections which the immune system cannot deal with precisely because it is being suppressed by drugs. The possibility of certain infections are combated with other drugs. Although the drug regime is strictly monitored and controlled, infections and rejection remain permanent threats to organ recipients. Consequently, they continue to take the drugs for the rest of their life. Three of the recipients I met had recovered from major episodes of rejection; others had had minor rejection difficulties, but suffered from infections which had forced their return to hospital or, at the least, to complete rest at home. Episodes of rejection or infection tend to serve as reminders that recipients do not have their own organ; it came from someone else's body.

Recipients can also be affected by other unpleasant physical and emotional changes, unsure whether they relate to the transplanted organ or not. One recipient joked that some patients felt compelled to tell TU staff about every little physical problem, for example "I've got an ingrown toenail, doctor. Is it because of the drugs?" Although most recipients will stress, at what one might term the level of everyday conversation, how well they are as a result of their operation, their ongoing physical problems can be challenging.

Emotional or psychological problems can be as severe as the physical ones, though not necessarily life-threatening. After the initial euphoria of recovery, one or two of the recipients I interviewed had been extremely dispirited about their slow rate of progress. Very few had found their long term recovery easy. Another change recipients noticed was a heightened emotional sensitivity, usually appearing in the proclivity to cry "at the drop of a hat," as Helen put it. The men found this more troublesome, commenting that crying was not something men were supposed to do.

Transplant recipients can be ambivalent about expressing any difficulties they are experiencing, either emotional or physical. As Tony remarked, "when people ask how you are, they don't necessarily want to hear the truth. It's just habit -- 'how are you?' 'Fine'." When Jo Hatton, one of the first people in Britain to receive a transplanted heart/lung, voiced some of these issues in a letter to *Transplant Times* (a newspaper produced from Papworth Hospital) subsequent issues carried some letters of praise, but more of criticism, from other recipients. The general view was 'you are alive, be grateful for it, and stop complaining'. In the early 1980s, Jo learned there was little supportive space for recipients to express anything but gratitude towards

the gift, but she fought to create it and established the Transplant Support Network (TSN) in 1995. Having established a network of regional group organisers composed of recipients trained in communication skills and who can offer information and support to anyone involved in transplantation, TSN has now begun to formalise links with transplant units throughout Britain by distributing an education pack.

Along with their own physical and psychological problems, recipients may have to deal with the deaths of other patients while they are recovering from their own operations, or in the longer term. The ones I met said deaths in the unit might have been easier to cope with if staff had not tried to hide what was happening. Doors would quietly close; curtains would be discreetly drawn; nothing was said "but we knew who had died -- word gets round." Hiding death in this way was similarly reported by Hockey (1990) in a nursing home for the elderly. Mirroring the comments I encountered from other health care professionals, about not talking to bereaved people, the TU staff I spoke to said it was for the benefit of patients, so they did not get upset. On the other hand, one long term recipient told me he felt very awkward asking staff about other recipients, in case anyone had died, and the staff were upset.

Witnessing the deaths of other patients during a hospital stay is not unique to transplant recipients. However, the possibility of a life-saving operation for those facing imminent death can mean potential recipients are not given the kind of emotional support increasingly available to other dying people to help them come to terms with death, a predicament noted by the senior nursing officer in a transplant unit. The death of a fellow patient, before or after a transplant operation, tends to emphasise the uncertainty of survival for others; no transplant operation carries a

guarantee of success. At the same time, surviving recipients can also feel guilty that fellow patients have died, and ask “why them and not me?” in a manner which resonates with the attitude of many recipients towards their donor’s death. This brings me to consider the conceptual inalienability of organs, for their recipients.

From generalised anonymity to ‘specific someone’

In the context of organ and tissue donation, Strathern argues, an “anonymously produced object becomes part of a store on which others draw” (1997:302), because of its alienability. Semen and ova are alienable, detachable from the donor, because they can be “produced [for use] without being elicited by another person” (1997:300). Women who donate ova have actually described them as being like fingernails (Konrad 1999:651), produced to be discarded.³⁸ Bracketing for the moment the finite nature of ova, as opposed to the regenerative nature of semen, reproductive tissue and indeed blood are also comparable with fingernails because they readily regenerate.³⁹ Here we have two contrasts with organs. In the first place, human organs are finite. In the second place, organs are neither ‘natural’ bodily emissions nor autoproductive; they cannot be produced without being ‘elicited’ by another -- a surgeon must remove them from the body. Strictly speaking, ova must also be ‘elicited’, i.e. surgically removed for the purpose of donation though they do form part of a regular bodily emission. The fact that organs have to be removed from *someone*, in the majority of

³⁸ Nevertheless, these donors expressed a sense of communion with recipients, which Konrad terms the sociality of anonymity (1999:643).

³⁹ The biomedical perspective is that female children are born with approximately seven million egg germ cells which diminish in number and quality throughout their lives (Konrad 1999:662n10).

cases from *someone who has died*, critically undermines the generalised anonymity enjoyed by their reproductive counterparts.

Yet, once again, we have a situation which manifests tensions and contradictions. TU staff have told me of recipients who do not think about their donor at all, who have felt that a transplant was their right. Staff can be upset by such sentiments, and one or two nurses explained that they would gently try to get recipients to give some thought to their donor and grieving family. Conversely, staff were concerned when recipients were regarded as 'dwelling on the death' of their donor, and thinking too much about the bereaved family. As for recipients, they struggled to find their own ways of coping. All the recipients I met were conscious of the fact that their continuing life derived from someone having died, and that there was now a direct link with the donor and his or her family, via the donor's organ. I do not mean, here, that donors are regarded as having died *in order that* their organs could be transplanted. None of the recipients I interviewed seemed to regard the donation as some sort of sacrifice, though many did speak of the generosity of the donor and his or her family. Rather, recipients were aware that they but not their donors had got a 'second chance' at life, that another family rather than their own had been bereaved.

Other aspects of receiving a transplanted organ can intensify a recipient's sense of connection to his or her unknown donor, and here I am suggesting a marked contrast with other kinds of body tissue. Promotional materials for donation certainly suggest that solid organs hold a comparable status with 'discardable' body parts. Donors are deceased, and hardly need their organs, which are therefore discardable as

dead bodies are discardable -- we bury or cremate them. Yet the difference is significant in its ambiguity. On the one hand, recipients did speak about their transplanted organ arriving "like a new washing machine" or being "like a central heating pump" -- a utilitarian, even commodified view.⁴⁰ Conversely, organs may be discardable but they are not waste products. From the perspective of someone who needs a transplant they are beyond price, and beyond being marked as anonymous.

somatic identity

A further factor working to destabilise donor anonymity is the point that the donor's somatic identity may well matter very much to the recipients of his or her organs. Human organs vary proportionately with body size, and while donor identities are generally a well kept secret, the recipients I met laboured to arrive at some conclusions as to their donor's age, sex and physical size.⁴¹ Jane said she thought the heart she received was from a healthy teenage boy because "I'm small ... I needed a small heart, so the donor had to be small, but I feel it beating so strongly, it had to come from a healthy young man." Robert similarly concluded that his donor must have been of a substantial build, and probably therefore male, otherwise the lungs would not have fitted the space available to them. He told me of other recipients who wonder about their donors and "make up what they don't know." Beyond this sort of musing over somatic identity, recipients would wonder about the family of their donor. Some might ponder on what their donor's family would think of them, like the

⁴⁰ 'Commodified' denotes treatment 'as if' a commodity, without the attachment of monetary value.

⁴¹ These examples reflect gendered assumptions about male and female physiology. I did not find gender an immediate concern for my subjects of study though it has broad relevance given the gendered nature of the Western 'individual'. Of greater significance here for 'imagining the donor' is the fact that external body size dictates internal organ size. Transplanted organs must fit the space.

recipient who wondered how the family would feel that the organ had been given to him -- "an old fogie" -- instead of a young person. While this resonates with the guilt older recipients can feel that they got a chance for life when younger people also need it, this particular recipient appeared to be managing his feelings very well. Many recipients, as I will presently illustrate, also enter into the grief of their donor family. Whether right or wrong in their assumptions, the recipients I met were turning an anonymous somebody into a specific someone, with a family who were mourning.

Lastly, and contrary to Western 'presents' which take on the identity of the recipient (Strathern 1997:295), organ recipients may hold ambivalent views about their control over their own identity, and wonder about the possibility of their becoming like their donor. One woman in the USA noticed such profound changes to her personality -- habits, tastes, behaviour -- that she felt compelled to contact her donor's family. They have confirmed that her acquired characteristics closely resemble those of her heart donor (Sylvia 1997). Several recipients I interviewed mulled over this possibility when they described various physical, emotional and behavioural changes they had noticed. Then they shrugged it off, saying "but I know that's not possible." Recipients can experience profound physical and psychological changes following their operation. Some of these, like an increase in body hair, can be linked to their regime of drugs. Others, like a heightened emotional sensitivity, are less easily pinned down.

Recipients also told me they were more inclined to 'seize the day', as it were. One male recipient, George, started to chat with me in the bar, after a day at the BODY Convention. It was quite early on in my research phase and, not the most

accomplished person at casual chat, I had been wondering how to approach Convention delegates, so I was grateful when he began the conversation. In response to my question about any particular changes he had noticed since his operation, George said, "Well, I would never have started to chat to a complete stranger of the opposite sex, in a bar!" Since his operation, he had been much more outgoing and did wonder if this was coming from the personality of his recipient. "They do say you can take on aspects of your donor's personality, and I can't help wondering ... then I think no, don't be silly. It's just because I've had a second chance, and intend to make the most of it." Even when recipients discount the possibility of taking on aspects of the donor's identity, they are aware of a specific, albeit anonymous, person who has died and left a family in mourning, and they may find that anonymity disturbing.

While the anonymity of their donor might unsettle, recipients could find contemplating the death of their donor, the grief of that bereaved family, and the magnitude of the gift they themselves had received an emotionally volatile combination. However, like the bereavement of donor families, I found that there were widely differing views among TU staff and recipients on the best way to manage these feelings of guilt and gratitude, as I now go on to discuss.

III Of Guilt and Gratitude

In their initial interviews, recipients spoke quite calmly to me about their illnesses, and with a contentment bordering on elation about their operation and the difference it had brought to their lives. Subsequently I found that below the surface, recipients were struggling, with various degrees of success, to come to terms with emotional ambiguities of their continuing life as a direct result of someone else's death. Most recipients said they would never forget their donor and would always be grateful for their 'gift of life'.

At the same time, while on the waiting list, recipients are hoping and wishing for an organ transplant, perhaps employing macabre humour to mask the realities of that wish -- that someone else die and leave a grieving family, instead of them. Consequently, recipients can feel 'survivor guilt' reported, for example, among survivors of Nazi concentration camps during World War Two (Myerhoff 1984). One or two recipients coped with their survival by deliberately not thinking about their donor and his or her family. As one said, speaking through tears, "If I thought about my donor, I just couldn't go on." Similar intense feelings arise when she hears of young people dying. "Why them and not me? It doesn't seem fair."

In this opening paragraph I have tried to convey what emerged very strongly during the present study; that feelings of guilt and gratitude, and ongoing health problems, all intertwine for organ recipients. When I first approached transplant units in the hope of gaining access to organ recipients, their emotional and physical problems were frequently emphasised as reasons it would not be appropriate for me to talk to them. In particular, talking about their donors would not be beneficial to

recipient's health and well-being. The physical and emotional difficulties faced by recipients following a transplant operation can certainly be immense; contrary to popular imagery, recovery from a transplant operation is not immediate. Yet I found recipients well able to inform me themselves if they did not wish to talk about their donors; most managed to discuss their feelings, albeit through occasional tears.

Directing Gratitude

When recipients spoke of the lifesaving nature of their operation, gratitude was invariably directed towards their transplant unit's staff, particularly the surgeon who was often regarded with awed respect. Feelings of gratitude can be magnified because other health care professionals had said "there is nothing more we can do for you." Transplant surgeons step in and throw the lifeline, or as one recipient had expressed it, dangled the golden key. Such intense respect was also apparent when a prominent transplant surgeon spoke at a BODY Convention I attended, where he was publicly thanked by a donor family (he had carried out the removal operation on their son), and by a recipient on whom he had operated several years earlier.

As this latter instance suggests, recipients also feel that it is the TU staff to whom they owe their continuing life, leading recipients to feel a strong connection with the transplant unit and staff. Several recipients told me they were reluctant to go abroad on holiday, in case they took ill far away from the unit. One couple gave up their plans to retire to New Zealand, despite assurances from the surgeon that health care provision was just as good there. Other recipients waited until they were into the second year after their operation before planning holidays. As one recipient bluntly

put it, “these people are keeping me alive” -- a reminder that the transplant operation is by no means the end of the matter. Considerable aftercare is also required by organ recipients, hence their ongoing links with the unit, and sense of gratitude to the staff. Transplant unit staff generally understood and accepted the gratitude expressed by recipients.

However, when gratitude was directed towards their donor, and recipients talked of expressing thanks in a letter, some staff overtly attempted to ‘conduct the conduct’ of organ recipients, to divert their gratitude into other channels. Various alternatives are available, as TU staff explained to me in interviews. One is to encourage the recipient’s own adherence to the aftercare regime: “Take care of yourself and the organ; that is the best thanks you can give.” Another path for deflecting gratitude to one’s donor lay in suggestions of fund-raising or campaigning for the transplant programme. Quite a number of recipients spontaneously enter into such activities anyway, knowingly or unknowingly responding to their ‘gift of life’ with a form of generalised reciprocity.

A third path was offered to some of the recipients I interviewed. They were asked by unit staff to speak to potential recipients or very ‘new’ recipients, and their families, “about having a transplant,” from the perspective of someone who had actually gone through it. Some recipients told me they did this anyway, without being asked. What was said depended very much on the individual recipient. Gail said the surgeon asked her to be honest, not to hide the problems, while Chris felt he had to emphasise the more positive aspects, not just to support those to whom he spoke, but

also for his own sake. He coped, he told me, “by ignoring all the negative stuff,” like episodes of rejection.

As these alternative and well-trodden paths for the expression of gratitude suggest, I was to discover that the issue of direct forms of communication between donor families and the recipients of their relative’s organs was a thorny one. Since this is a material manifestation of connectivity, I give the issue some attention.

Direct(ing) communication between recipients and their donor family

The degree of communication permitted between recipients and donor families appears to be a matter of transplant unit policy though my research suggests that there is no uniform approach to formulating such policies. The subject sometimes created what I rightly or wrongly interpreted as an aura of discomfort among transplant unit staff when I raised it. Some said it was “not unit policy” to allow communication between recipients and their donor’s family; others offered a more personal point of view, saying they did not think it was a good idea. A senior surgeon admitted that his registrars possibly discouraged recipients from thinking about contact with donor families, though letters would be handed on if recipients wanted this to be done. I am aware of one unit where the co-ordinator could apparently overrule the wishes of the senior consultant. Another co-ordinator told me “we don’t listen to managers” and a third would “argue strongly” for what she feels is the best service.

In practice, I found a continuum of communication control. At one end is the situation of a recipient who said he had to promise not to ask for any information about his donor; it seemed to be “the way things were done” in his unit. Where it is

permitted, communication usually takes the form of letters of thanks conveyed either from the recipient to the recipient co-ordinator, from there to the donor co-ordinator, and on to the donor's family, or vice versa. On route, letters could be screened to ensure maintenance of anonymity; in one example known to me this involved covering names and addresses with sticky labels. I also learned of two units which provide a small leaflet with suggested points to put into the letter. In one leaflet, recipients are told that they must not give their name or address to the donor's family. Another recipient said his unit had standard, but attractive, cards with the donor's first name on them. All recipients had to do was sign it. At the other end of the continuum is the co-ordinator team at Birmingham's Queen Elizabeth Hospital, which has for some time facilitated face to face meetings between recipients and their donor's family, if both parties wish to do this.

In contrast with the idea that it is better for recipients not writing to donor families, I suggest that writing might offer a sense of completion to the gift transaction, if not to any ongoing feelings of connectivity. Cunningham's (1998) survey bears this out; the co-ordinator encourages recipients to write letters, and provides them with practical guidance. There was no evidence to suggest that recipients were emotionally harmed as a result. Attempts to direct the thoughts of recipients away from their donor and his or her family have limited potential for success, without significant efforts on the recipient's part, and it could be argued that denying recipients the opportunity to send a letter of thanks can also be detrimental to their recovery.

Like deciding whether or not to talk to me about their donors, recipients demonstrated the wish and the ability to reflect on the question of communication with their donor's family, and to reach their own decisions. At the same time some decisions reflected assumptions about donor families which, as Chapter Four has shown, do not necessarily accord with the assessments of donor families themselves. And so we are compelled to return to donor families, implicated in the lives of organ recipients as much as recipients are implicated in the lives of those donor families. To conclude this chapter I present comments about inter-family communication, emerging from recipients and donor families in interviews and questionnaire responses.⁴² These comments reflect central themes and foci from the current chapter, and offer an introduction to Chapter Six.

I asked all the recipients who participated in my research if they had tried to write a letter of thanks to their donor family. The majority of recipients had written letters, often with encouragement from transplant unit staff, and were glad they had done so. Responses to my survey were returned with comments expressing the sense of relief, or of joy, which writing had brought, and the even greater joy of receiving a response from their donor family. Sadly, some recipients had no idea whether their letter reached its destination. One respondent had tried to ask unit staff to find out for him, but all they would say was "it was passed on to the hospital where the donor died."

A small number of recipients had wanted to write, but transplant unit staff would not allow it, or else they got the strong impression it was not 'the done thing'

⁴² Quantitative data from the survey are reproduced in the Appendices.

in their unit. Mary's situation is illustrative. Despite her emotional problems, she would have liked to write to her donor family, but understood this was frowned upon by the transplant unit staff. I later discovered that recipients in this unit are told they must not ask about the donor, but letters of thanks will be passed on to the family if recipients wish to write. It was suggested that my informant misinterpreted the information, though I met staff from this unit at an early stage of my research and must admit I interpreted their description of 'unit policy' in the same way.

A few recipients who had not written letters wondered, "How do you thank someone for your life?" This question was usually accompanied by comments on the lack of information recipients get about the donor and family. Not requesting information about donors may be pressed home as strongly as that of not asking about writing. These recipients felt it was impossible to write when they did not know if the donor was male or female, young or middle aged, and what relationship they had had with surviving family members. While there is validity in such comments, I have seen two anonymous letters, sent to donor families by co-ordinators, which offer a different perspective. The first letter was not from someone who had benefited from that family's act of donation, but the co-ordinator had felt the simple words were so sincere "they apply to all donor families and I'm sure you will find it uplifting." The second letter was written by the recipient's wife. Both expressed the difficulty of thanking a donor's family for their life, when they were in the midst of bereavement; the families who received these letters said they were touched by the sentiments.

The physical frailty of recipients, after their operations, was often cited by TU staff as one reason why recipients could not be expected to write to their donor

family. At the same time, judgements about the appropriate time to write reflected assumptions about untimely or inappropriate intrusion into a family's grief. One recipient said by the time he felt able to write, he thought it was too late -- but he "regrets this decision more strongly with every year that passes." In one unit, it was felt that writing eight months after the recipient's operation was too soon. Another recipient said it was at least a year before he could give any thought to his donor's family and by then it was too late to write. In Cunningham's (1998) survey, letters were sent as far apart as one month and six months from the date of the recipient's operation. Four respondents to my survey wrote more than a year after their operation. Mirroring Cunningham's (1998) findings, no donor's relative who completed my questionnaire made any comment about the untimely arrival of letters from recipients. Indeed, I have seen a letter written by one recipient fourteen years after his operation. Unable to trace his own donor, he sent the letter to Jane and David Nix, who set up the Midland Donor Family Support Group. They were delighted to receive the letter, stressing that "it's never too late to say thank you."

The issue of expressing gratitude for the 'gift of life' requires careful consideration. Donor families have told me that they do not expect thanks for what they have done; any gratitude expressed by organ recipients is deflected by them, on to the donor. Conversely, I have not encountered any situations where a donor family refused to accept a letter of thanks; they seem rather to be highly valued, symbolising the generous nature of the donor and are treasured as such, possibly kept in an album with photographs of the deceased (Plate 11).

Expecting thanks

I did encounter a situation where a family *expected* thanks and it created considerable discomfort among those present. It happened at the BODY Convention in 1997. A distinguished transplant surgeon had just given a potted history of its development, resonating with the 'heroic journey' outlined in Chapter One's historical review. We were a few minutes into the question and answer session which followed, when someone asked why donor families received no thanks from the recipients whose lives had been saved. He and his wife had agreed to the removal of organs from their son; seven people had benefited, as they learned in a letter from the co-ordinator, but they had expected letters from recipients. "Why didn't they write? Weren't they grateful?." I was sitting behind the couple and had observed their distress throughout the presentation; I now also saw their anger at this apparent lack of gratitude. The speaker said something which I did not catch -- all my attention was taken up by the couple. Discussing it later with Tom and Catherine, Tom said he was furious at the speaker's reply -- that families are not supposed to expect thanks.

By the time I had drawn my attention back to the hall, a silence had fallen. People looked at the floor, the ceiling, sometimes at each other, but no-one spoke. The silence stretched on -- until the anthropologist, more fool than angel, stepped in. I read my own interpretation into the silence, and sought to offer a reply without the embarrassment I assumed others must be feeling at this overt expectation of gratitude. With apologies for presuming to speak in the place of any recipients present, I began to outline the diverse policies of transplant units, which may discourage any form of contact between recipients and donor families, as well as the problems many recipients

still have after their operations, guilt over the death of the donor being a significant factor. John Evans, in his capacity as Convenor, then pointed out that this was not the time or place to discuss the issue, and suggested we focus on asking the speaker about current and future developments in transplantation.⁴³ Questions turned to how the number of donors could be increased. By the time a recipient had recalled a humorous story about his operation, which the speaker had performed, the atmosphere seemed to relax.

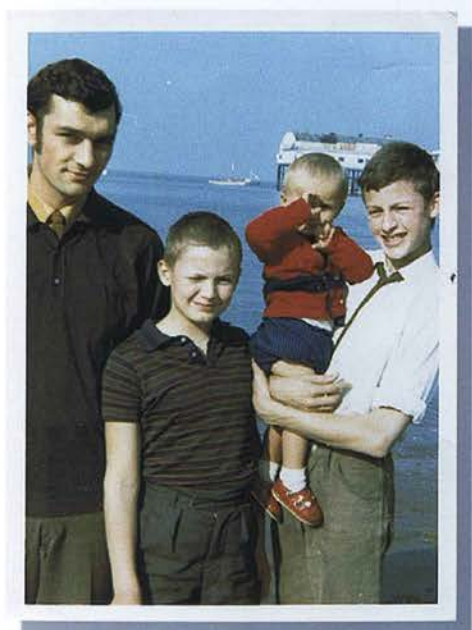
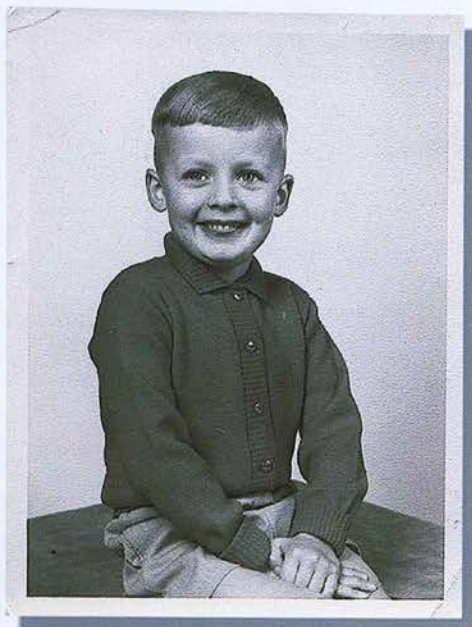
When I spoke to the couple -- Rita and Conrad -- later, they said the surgeon had seemed embarrassed by the question and maybe he was not the person to ask but, after all, it was he who did the operations. However, they had not realised that recipients could be ill after their operations. They have managed to take this on board now, but it has remained difficult for them to accept that recipients can feel guilty about being alive. Fortunately, at the BODY Convention, they met other bereaved couples, a recipient who spent a great deal of time with them, and a senior nurse from their home town who was able to find out more about the recipients of Philip's organs. All these gestures of concern have helped them to feel less isolated, sadly a common occurrence for many bereaved people.

Summary

This chapter has reviewed and questioned some of the arguments against any kind of direct communication between donor families and the recipients of their relative's organs. Whether all organ recipients should be required to write a brief letter of

⁴³ John and his wife Margaret founded the British Organ Donor Society when their son died and became a multi-organ donor. The topic was further discussed at BODY's AGM the next day, which I could not attend.

thanks -- which may well be enough for most donor families -- I leave to those who decide such matters of policy. From my research, I would argue that organ recipients may well derive far more emotional benefit from performing this tangible expression of gratitude, than they do when the choice is taken from them by others, albeit acting 'in the patient's best interests'. This is not to imply that 'making a return for the gift' cancels all sense of obligation. The transacting of human organs, as it was conducted by the participants in this study, bears scant resemblance to transactions of a commodity form where the relationship is between the objects exchanged, say, 'letter' for 'organ', the reciprocal exchange thus cancelling the relationship. As I have argued, donor families and organ recipients both participate in the intangible substance of the donor which accompanies the organ and thus establishes not just a connection, a 'between', but a connectivity, whereby "the self [is] defined and experienced through an array of significant relationships with others, past and present, living and dead" (Battaglia 1990:188). It is to the tension between connectivity and autonomy in the organ donation and transplantation process that I turn in the last Part of this thesis.



Images from a Life: Son, Brother and Uncle

Top left; Photo 1: Philip, aged eighteen months

Top right; Photo 2: Philip aged four years

Above left; Photo 3: Conrad and his sons, Robin, Glen and Philip, the eldest

Above right; Photo 4: Rita with Philip and his nephew



Photo 5:
Some of the many messages of condolence received by Rita and Conrad when Philip died. His photograph is to the right of the mirror



Photo 6:
Conrad at Philip's memorial



Photo 7:

A photograph of John, surrounded by commemorative albums



Photo 8:

Photos of John's memorial tree and its certificate. BODY arranges the planting of these trees in memory of deceased donors and recipients

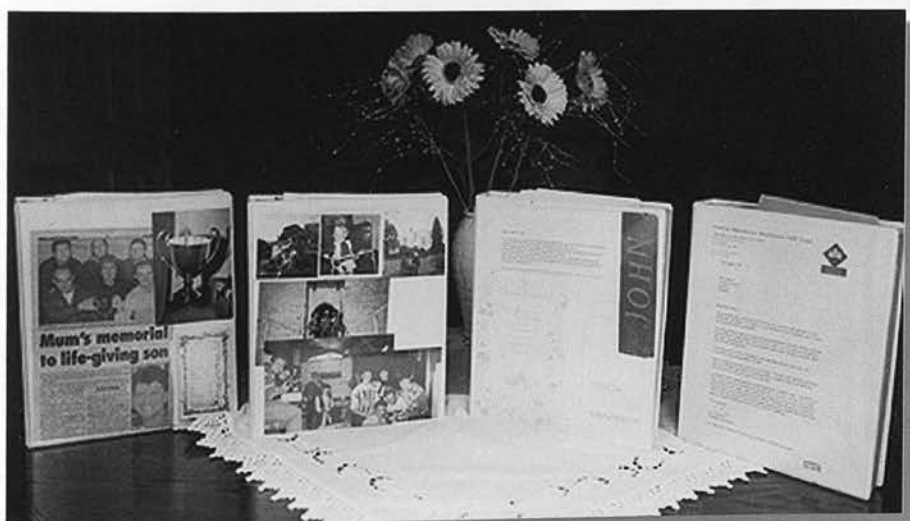


Photo 9:

A collection of cards, newspaper articles and letters commemorating John's death and act of organ donation



Photo 10:
Looking towards John's garden from the house



Photo:11
Tom and Catherine created this quiet area as a memorial to John



Christmas card designed in John's memory by his father, Tom

Right; Photo 12:
John as a young boy



Below;
A Mother's Day Card for 2000:
John continues to be a part of
his family's life after his death



PART THREE REVISITING THE WESTERN PERSON

Chapter Six

From Sovereign Individual To Connective Self: Personhood As Multiplicity

Throughout the course of the current study I was constantly called to reflect upon tensions, ambiguities and inconsistencies within the performance of organ donation and transplantation. The transacting of human organs can be understood as voluntary and coercive, organ donors can be anonymous and all too poignantly familiar, human organs are treated as detached objects yet they can also be invested with the emotional significance and connective capacities of valued and cherished memorabilia, the very thought of which recalls to mind the person to whom they once belonged.

This chapter draws together all these shifting perspectives on organ donation, tracing one more path from individualism to connectivity. Within three broad sections, I offer fleeting glimpses of bodies, organs, individuals and persons, none of which would stand still to be unequivocally named.

Section One locates organ donation within hegemonic discourses of consumer values and political individualism, where social responsibility and civic duty reside in tension with individual rights.

Section Two looks at the shifting and inconsistent perspectives which emerge within what I shall very broadly term 'the clinic' -- encompassing promotional literature, official and unofficial policies and codes, and the individual views of health care professionals and lay people.

Section Three returns to donor families and organ recipients whose self-making has been profoundly affected by their participation in the transacting of human organs.

I Individual Rights and Consumer Values

O'Neill (1985:85) has argued that "capitalism desires, in terms of its own technological myth, to replace human beings with machines [and thus seeks to produce] a consumer or service society [of] beings whose rights and duties are defined through the therapeutic state." He further contends that capitalist societies consist of "competing and incongruent interests whose ... affiliations are modified by the ideology of the public good" (O'Neill 1985:89). Bracketing the suggestion of a 'higher order of entity', namely Society, in O'Neill's argument, and recalling the reader's attention to my alternative of 'jural individuals' and 'the nation-state' (above, p.55), aspects of O'Neill's analysis of contemporary Western consumer societies resonates with issues which arose in the context of the current study. Within the UK's therapeutic state, where bodies are defined through a medical model (Crossley 1996:111), and health has become a consumer issue (HMSO 1995), organ donation and transplantation are understood to be a common good, organs not to be wasted. Taking autonomy to its extreme conclusion within a doctrine of political individualism an organ transplant becomes a right.

Recycling -- you know it makes sense

In a letter to the *Daily Express* (6.4.00) Steve Belk deplores the fact that nurses do not support legislative change to a system of *presumed consent* (see below). Briefly but graphically illustrating one of the many restrictions he faces as someone with kidney disease, on dialysis, and commenting that a transplant operation is less costly, Mr Belk asks, "Does it still make sense to waste all these organs?"

For 'waste' we can read the burial or cremation of organs because, in this particular context, individual people have not made the effort to translate their support for organ donation into formally registering or carrying a donor card, a view which surfaced frequently during my research. Consequently I am suggesting that the 'altruism' of organ donation today is undergoing a metamorphosis into 'political correctness'; using the otherwise 'wasted' organs of the dead to save lives has become an almost routine clinical practice for which unconditional approval and compliance are expected, even demanded, as a social responsibility -- leaving limited moral space within which it can be questioned.

Contributing to this situation, the provision of health care in Britain has been subsumed, during the late twentieth-century, under a rhetoric of individual rights. A high standard of health care has come to be expected; indeed one's right to it has been enshrined in the *Patient's Charter* (HMSO 1995), part of the *Citizen's Charter* instigated during Margaret Thatcher's sojourn as Prime Minister. In a 'Foreword' to the *Patient's Charter* Ian Lang, then Secretary of State for Scotland, emphasised choice and value for money as central entitlements in health care (HMSO 1995). Patients have been transformed into consumers (cf. Strathern 1997).

In my conversations with transplant recipients, the financial costs of Britain's health care system were considered, and it was acknowledged that an extremely disproportionate amount of money was available to us, in Britain, when contrasted with many poorer nations. Yet, as recipients also acknowledged, "it's what we expect." Recipients themselves did not speak directly in terms of having the right to a transplant; they were instead overwhelmed by feelings of gratitude, and guilt, at

having been 'the lucky ones'. Those still waiting may understandably have very different views, echoed by the relatives of people who died without a transplanted organ.

The Right to a Transplant

An article in the *Scotsman* newspaper (29.4.97a) carried almost a full-page report about a fatal accident inquiry into the death of a young girl, Michelle Paul, in 1995, as a result of taking the drug 'Ecstasy'. This caused liver failure, but she was rejected as a transplant recipient by Edinburgh Royal Infirmary. The newspaper also featured a response from Jim Baxter, a former Scottish football player, who received two transplants (*Scotsman* 29.4.97b). His situation had been referred to by Miss Paul's grandmother, at the inquiry. She wanted to know why 'a former alcoholic' got two transplants and her granddaughter was refused; she clearly felt her grand-daughter had as much right to an organ as anyone else.

While the distress of Miss Paul's family is understandable, this perspective reinforces the idea that health care professionals should be obligated to save lives. Organ transplantation is viewed as a right. Donors and their families are ^{not simply} beyond anonymous; they are absent and, as my frequent and deliberate use of the term illustrates, human organs have been transformed into a clinical practice, 'a transplant'.

II Imagining, Acknowledging and Severing Connections

A study of the messages carried in organ donor cards found that 'altruistic behaviour', i.e. the willingness to donate organs, had to be elicited through empathy arousal; the best way to provoke this was to include an emotive story (Skumanich and Kintsfather 1996:401-8). One of the two messages tested "was prefaced by ... an emotive media story concerning a person undergoing a transplant procedure" (Skumanich and Kintsfather 1996:404). Readers can imagine a connection with a 'real person' whose situation motivates them to act; it is an attempt to 'conduct their conduct'.

Promotional leaflets produced and distributed in the UK illustrate these analytical points. Anonymity, as a feature of organ donation, vies with the provocation of 'imagined relationships' -- potential recipients could be people like us - - which call forth our care and hopefully our generosity by registering as donors. Three leaflets came to my attention, in serendipitous fashion, during my research. The changes identifiable in form and content illustrate how the 'voluntary, unrequited surrender of resources' turns into subtle and not so subtle coercion.

Giving to Strangers: eliciting organs through imagined relationships

The leaflets reproduced in Plates 1-6 provide, with various degrees of concreteness, textual images of potential and actual recipients. What follows is my own interpretation; the reader may reach other conclusions. In the first leaflet, particular though brief mention is made of people whose lives could be improved with a transplanted organ. In the second leaflet, 'real people' speak directly to the reader through quotations; a potential donor talks about giving life to others; two recipients

describe the dramatic and positive change a transplant has made to their lives; a donor's relative expresses the comfort derived from knowing that donation "will help to bring joy to somebody else." Providing an opportunity for spontaneous altruism is clearly not sufficient. This is a 'feel good' message, directed towards the public, to encourage registration as a potential organ donor. The message is about happy, healthy recipients, a comforted though bereaved family -- and responsible citizens who identify themselves as willing to donate organs. It says 'look what you could do, if only you carried a donor card or joined the Register'.

The second leaflet also carries photographic imagery but who is it we are looking at? Are they potential donors and recipients, with families and friends? Or the relatives of actual donors? One cannot say for sure but this is part of the power of the message -- we can imagine them to be ^mwhoever we want. Taken as potential donors, the people featured in the photographs span a wide range of ages and ethnic backgrounds, emphasising that anyone can be a donor "in the right circumstances."⁴⁴ The leaflet's general message of optimism contrasts with a small photograph of a youngish man wearing a rather pensive expression. Placed above the quote from a potential donor, it appears to reflect the sentiment -- some careful thought being given to "when I die."⁴⁵ Having made the decision, one can get on with living, assured by the fact that, when one dies, one's organs will be available to save other lives.

As families and groups of friends, including potential donors or recipients, the photographs reflect significant relationships, the joys of life, and continuity of the life

⁴⁴ The right circumstances refers to the fact that donors must be declared brain stem dead, and organs must be healthy.

⁴⁵ Alternatively, a colleague suggested it could be a recipient, considering his donor's death, though I feel this would tend to detract from the general 'positive' message about recipients.

cycle. One photograph features a wrinkled, grey-haired man towards the end of life, and a small girl just beginning hers. Are they grandfather and grand-daughter? A second shows a young adult woman giving a small girl a 'piggy-back'. Are they mother and child? A third photograph features three young people studying what could be a map. Are they college friends planning a holiday of discovery and adventure? Whoever they are, I am suggesting the photographs depict the sort of relationships which draw forth our care, commitment and love. In doing so, they seek to elicit the desirable empathetic response of signing a donor card or placing one's details on the Register.

These relationships offer further suggestions about why one should consider donation. The sad image suggests these little girls are too young to lose their mother or grandfather, and are certainly too young to die. Similarly, the college friends are too young to be separated by death. Alternatively, on a happier note, another photograph of an older man has been placed next to the quote from a recipient, explaining how he was able to continue working until his retirement. He and the other older man were not old enough to die. They still had much to contribute to society, and have been able to do so, thanks to a transplant operation. Paradoxically, given the notion of individual choice presumed to apply to organ donation, which stems from the politically dominant ideals of individual autonomy and independence, the very *interdependence* of the people in these relationships forms the implicit basis for making each one's survival an urgent, essential, social issue. They are socially (and economically) productive people, and will continue to be so -- if given a transplant.

What of the imagery in the third leaflet? The verbal message offers a theme of continuity through the phrase "So life can go on." Concern towards potential recipients and their families is strongly evoked through confrontation with the idea that 'it could happen to you'. Readers are explicitly invited to contemplate the possibility that we, or someone in our family, might need a transplant operation. How would we feel? Think of our own grief. Now think of the grief of others. Concern for others is also evoked through the use of the heart motif. Not only is this one of the organs which can be donated; Helman (1991:2-3) argues it is "a universal symbol of emotion, courage, intimacy and will." While the cross-cultural applicability of this symbol could be challenged, the heart literally embodies some of the most provocative metaphors in the English language. Many refer directly to love (Youngner 1996:51; Doniger 1996:207). Hearts adorn the gift wrap and cards and even the presents we give to and receive from our loved ones as selfless and free expressions of regard; the heart serves as a symbol of the spirit of altruism in our gifts.

Acknowledging Connections: notions of 'family'

By adopting the foregoing approach in promotional materials, health care professionals acknowledge 'something' beyond the autonomous, separate, jural individual. Superficially, one might call it kinship in the narrow sense of that word, meaning consanguines or affines. Where the women in Konrad's (1999) study could not name the 'something' which connected them to the anonymous recipients of their ova, Konrad suggested 'the sociality of anonymity'. I am arguing that the 'something'

health care professionals acknowledge is the connectivity of personhood, though the full significance of that connectivity may not be appreciated.

Who counts as family?

In the actualities of human organ transactions, shifting, fluctuating ideas are apparent about families and how they are constituted. Here individual rights, as they are established in legislation on the transacting of human organs, may conflict with the connectivity of families and the need of bereaved people to be involved in decisions about what happens to their loved one's body.

On point of law, where a hospital patient can be positively identified as an organ donor, the Health Authority or its "designated representative" is empowered to remove organs without approaching the family; where the patient cannot be identified as an organ donor, organs may only be removed if "reasonable enquiry" has been made to ensure that neither "the deceased" nor "the surviving spouse, partner or any surviving relative" would object (Dept. of Health 1998:10, 13) . In practice, health care professionals do make every effort to approach family members for their views, though quality of those approaches might be interpreted variably. I am not aware of any recent situations where organs were removed from a hospital patient contrary to the stated wishes of his or her family members.

Of course, there is already a context in which a family may not actually be approached at all. Health care professionals are not legally obligated to inquire about the possibility of organ donation, and they may choose not to approach the bereaved parents of deceased babies and children, because these deaths are considered to be

particularly traumatic. Baby deaths are simply 'wrong' in a country with a very low infant mortality rate. Indeed, a personal friend of mine astonished the local donor co-ordinator by asking about donation in the event that her very ill baby were to die⁴⁶. The co-ordinator had never been involved with a donor so young, and she had to prepare special paperwork.

Spouses, or parents in the case of unmarried people, tend to be the ones who are sent any information about how their relative's organs were used. In one case, this caused a substantial degree of distress to the mother of a young adult woman who became a donor. The woman's husband was legally next of kin, but he declined to receive any information about recipients of his wife's organs. The donor's mother was not aware she could ask for information independently, though she did say, "to be fair to the co-ordinator," that she might have been told but, at the time of her daughter's death, she could not take in anything that was being said. In another case, the deceased's estranged sister was given priority over her house-partner of thirty years.

Severing Connections

When, in conversations with me, transplant staff expressed doubts about maintaining long term communication with donor families, it was often in the context of the possibility of a recipient's death. Learning about this would be too distressing for the donor family, it might suggest that something had been wrong with the organs, that they had failed in some way -- an unhappy reflection upon the donor. At the time, the point seemed reasonable, though I have subsequently wondered about the situation

⁴⁶ Child donors are treated 'as if' they were adults, "providing the child is of an age when it is reasonable to believe he or she would have understood what [organ donation] involved" (Dept. of Health 1998:15). This applies to the legal and ethical issues dealt with by the *Code of Conduct*.

where more than one organ was donated. One could surmise that the distress of learning about one death was seen to outweigh any comfort derived from knowing there were other surviving recipients. Conversely, my own survey showed that while donor families would be sad to hear about a recipient's death, none felt the information was inappropriate. A few the families had actually received this news. Rita has now learned that five of the seven recipients of Philip's organs have died. Those families I have come to know as friends consider that at least recipients had got a second chance for life, which was rather more than could be said for their loved one.

The possibility of recipients becoming emotionally attached to their donor's relatives, or vice versa, was considered to be sufficient reason for preventing communication. The point was illustrated to me through two similar stories from two different co-ordinators. Basically, a donor's surviving widow writes a 'very emotional' letter to a male recipient, which would have put undue stress on the recipient had the letter been passed on. In a version with a twist, another co-ordinator cited an example of a very emotional letter from a recipient to his donor's family, which would have been equally distressing to them. Emotional dependency of this sort was viewed as harmful to a bereaved person, if it prevented his or her progress through the bereavement, and harmful to ~~transplant~~^{organ} recipients, since it could exacerbate their already strong feelings of guilt or of gratitude.

Both of these examples sit awkwardly, to say the least, with the imagined relationships evoked in promotional materials where we are explicitly called upon to consider becoming organ donors for 'people like us', people we love and care about. In actual cross-bodily transfers of human organs, donor families and recipients may be

expected to ignore these emotional ties for the sake of their own well-being or, paradoxically, the well-being of the other.

Yet, I am suggesting that the kinds of people we can glimpse in such perspectives are not persons; they comply with the depiction of 'individual people' in Chapter Two, "linked *merely* by 'social' or 'emotional' or 'moral' relationships" (Bloch 1988:16, emphases in original). But they do not reflect the kind of self-making donor families and organ recipients appear to be engaged in, through "mutable entanglements with other subjects' histories [and] experiences" (Battaglia 1995:2).

Severing connectivity

Those who decide to formally indicate the wish to become an organ donor in the event of death are urged to discuss the matter with their family. In the midst of bereavement, relatives should not have to be making decisions about donation. In a paradoxical twist, though, the pain of bereavement has also been cited as a reason for excluding families from the decision-making process.

The 'constant refrain of shortage' which underpins public campaigning on organ donation foregrounds a discrepancy between those who express support for organ donation and those who actually register their wish to become a donor. An absence of any such tangible declaration can lead families to decline organ removal in the event of their relative's death. During the present study, in an effort to rectify this discrepancy, the British Medical Association began pressing the government for a change to the law, in favour of *presumed consent* -- 'opting out'. Arguments in favour of *presumed consent* rest on the assumption that the shortage of donor organs exists

because people do not take action to formally record their wishes. *Presumed consent* would mean those in favour of donation, currently the majority of the population according to statistics, would be saved the hassle of having to formally register as donors while those not in favour, currently the minority, would have to take action to register objections. The advantage to potential recipients also seems clear - more organs would be available. In media coverage following the BMA's announcement to press for legislative change, public opinions seemed reasonably evenly divided, though I cannot claim to have conducted a systematic review.

My own interest in *presumed consent* lies in its potential impact on bereaved families. A weak form exists whereby the family is still consulted; the strong form excludes them altogether. Excluding the potential donor's family can be justified from two opposing directions. In a radio debate on the issue (BBC Radio 4, '*Woman's Hour*', 5 Feb. 1999) Dr. Michael Wilkes, then chairperson of the BMA's Ethics Committee, presented the exclusion as being in the best interests of the family, who were already going through enough grief, before going on to emphasise the number of people waiting for kidney transplants. Approaching the issue from the other direction, so to speak, Mrs Elizabeth Ward, President of the British Kidney Patient Association (BKPA), has stated that "Our next of kin should have no right to overrule our wishes. If you've declared your wish to be a donor that should be the end of it." (*Daily Express* 3.9.96).

Excluding the family from the decision about organ removal is questionable in its possible quantitative impact upon waiting list figures. John Evans of BODY has spoken publicly on many occasions, about its probable detrimental qualitative effects

on bereaved families. In conversations with donor families, organ recipients, representatives of various voluntary groups, and health care professionals, I found that *presumed consent* as 'having to opt out' was contrasted unfavourably with the present system of 'choosing to donate'. The latter system clearly felt as if it offered a greater element of free choice, since action -- obtaining a donor card or formally registering -- was only required if one wished to be a donor. Similarly, excluding the family from the donation process was also viewed with disapproval. Discussing it with Tom, he regarded the idea as offensive. Were it to proceed, in a strong form which excluded the family from any role in the decision about organ removal, potential organ donors may have more rights, but families would be assumed to have no connectivity. Such a view of persons as jural individuals clashes with the findings of my research where the need to openly enact relationality with 'the other' could be compelling.

III Making Selves, Making Others

Imagining the other as self

On the first anniversary of John's death, Catherine telephoned the co-ordinator to ask why no more information had been sent about recipients. The shock and numbness of grief had eased and she realised she wanted to know more about them. The co-ordinator said not everyone wanted further information, and also that bereaved people tended to move house within a year of the death; it was hard to stay in touch. Catherine was very angry at what she perceived as excuses, and she "had a go" at the co-ordinator. She begged for information -- were the recipients old or young, male or female, still surviving, where were they from -- anything, but the co-ordinator was adamant. Nevertheless, a few days later, she received a letter from a recipient of one of John's kidneys, which meant a great deal to her, as her own grandmother had died of kidney disease. Catherine "felt proud," she told me, "that John had helped someone in this way," engaging John's act of donation as a personal link between a (no longer) anonymous recipient and a loved member of her own family. Concurrently, Catherine can be understood imagining herself as other, in the manner evoked by the third promotional leaflet described above (Dept. of Health 1998); she, too, had a dearly loved relative who might have benefited from a kidney transplant.

Imagining Identities

The story told to me by Robert provides a forceful example of the attempts recipients may feel compelled to make to turn their anonymous donor into 'a person',

concurrently illustrating in sharp relief that 'making the other' inevitably also involves 'making the self'. Robert had already concluded that his donor must have been "a big man, like myself," otherwise the lungs would not have been able to "do the job." Recovering from his operation, Robert also overheard a member of staff recalling when "the surgeon had gone to such and such a town to get..." stopping mid-sentence. As Robert understood it, the location of a donor had been inadvertently revealed -- let us call it Anytown. Over the course of the next few weeks, as he recovered from his operation, Robert created an elaborate story in his imagination. *He went to Anytown and consulted newspaper death notices for a mature male who had died suddenly, in hospital, just before his own operation. He found one, and turned up on the doorstep of the widow. She was distressed and sent him away, but he persisted, leaving his own wife and children in order to move to the same town as his donor's family.* At this point the story "began to take on a life of its own," with Robert "watching himself" *stalking the donor's children to and from school.* No matter how hard he tried to imagine a different ending, Robert told me he kept getting drawn into this one, and eventually forced himself to stop thinking about it altogether. Fond of a good story, Robert related this one to me with dry humour. At the time, the 'self' he had defined through his indeterminate relationship with his donor's imagined family was "very scary."

I have no intention of attempting to analyse this story in the manner of a psychological evaluation, but I will offer Robert's own interpretation. He said he felt a sense of responsibility towards the donor's family, whoever they were and, five years

later, he did still wonder about his donor. He mused on the possibility that he made the story up because he could not make actual contact with the family.

These two examples have illustrated how donor family members and organ recipients make imagined persons; neither has been intimately implicated in the history of the other -- until the actual transaction event. In sharp contrast, I turn now to consider how families remember their deceased relative.

'Like a bright spot': the present absence of organ donors

Thinking about how donor families remember their relative recalled to me the closing words of Battaglia's ethnography of death rituals on Sabarl (1990:199). One informant said remembering the dead was like the bright spot left behind when a mark is scrubbed off the floor. There is an absence but also a presence, evoking remembrance of what used to be there. For donor families, their relative is poignantly present in photographs and personal belongings, concrete expressions of a lifetime of memories (see Plates 9-12).⁴⁷ What they do not have is a future together though even this can be turned into a consoling thought. As Tom remarked, "John will always remain 24 and never grow old."

He had written to me, in response to a letter of mine which had coincidentally arrived close to John's birthday. This can be a very hard time for families, as is the time of their relative's death. Significantly, recipients can treat the day of their transplant as a second birthday. Rita has spoken of this with distress, especially incensed when one recipient, in a newspaper report, said it was like winning the

⁴⁷ Contrastively, recipients have no concrete details of the donor's physical appearance, personality or background, but as we have seen, recipients may endeavour to sketch in an identity.

lottery. People may applaud the use of organs for transplantation, and emphasise its life-saving potential, but for donor families organ donation can be suffused with a deep ambivalence. The date of a transplant operation may be celebrated by recipients and their families, but for donor families the anniversary of the donation event can be, as Rita said, "a tragic time." Someone suggested she write to a newspaper or magazine to say how she felt, but her husband pointed out that "it wouldn't go down very well with the medical profession." As I remarked earlier, donor families may be reluctant to voice their variegated experiences, since they do not wish to appear to be jeopardising organ donation.

Expressing doubt or mixed feelings about donation are complicated by the fact that particular problems may seem, on the surface, to have nothing to do with donation. Although the donor families I have interviewed have been traumatised by different aspects of their participation in organ donation -- from their treatment by ICU staff to a lack of information after the donation event -- all are ultimately linked. As intimately implicated in their relative's dying and death as they were in his or her life, these families do not perceive their loved ones as detached, autonomous individuals, nor their bodies and body parts as detached, alienated objects in the manner of impersonal items of property. A donor's family may find it hard to disconnect the person they know and love from his or her corporeal body, and impossible to disconnect the organ from the donor.

Tom remains ambivalent about agreeing to the removal of John's organs although at the time he was prepared for the question. His fears came to centre on what he allowed to happen to John's body. "Not religious myself," Tom had never

wondered about an afterlife and was not concerned about what would happen to his *own* body after death, “but it’s different for John’s body.” Although John carried a donor card, and Tom knew he was following his son’s wishes he is deeply troubled now about giving his consent to organ removal. As he said, “John made the choice but we have to live with the consequences.” When we first met, a year after John’s death, Tom was having difficulty accepting that John was dead and the fact that parts of his body were “scattered all over the country” was almost too much to bear.

Tom and Catherine have displayed very different levels of interest about the recipients of John’s organs. Catherine needed to know them as specific people, and that need developed over the first year of bereavement. Receiving a letter from a recipient of one of John’s kidneys enabled Catherine to establish her own connectivity with that person and her own grandmother. Originally, Tom had no interest at all in recipients. His fears about John’s dispersed body precluded such thoughts. Five years on, he tends to view his concern for the recipients as ‘grand-parental’ -- “the once-removed love for your child.”

In Chapter Two, I suggested human organs were ‘a kind of property.’ I have found it helpful to consider that, for a donor family, the organ is more in the nature of an heirloom, handed on from one family member to another, but where the original owner is always remembered. This is not to suggest that bereaved people require the presence of a body or body part to facilitate remembrance of the person who died. I am arguing that, for the donor’s family, the organ will always be first and foremost the donor’s; it is simply now in someone else’s keeping. Yet it carried with it the narrative of the donor’s life and death, intangible substance intermingled with the

narratives of those left to grieve, and those who received the organs. For this very reason, a donor family may be intensely curious about recipients of their relative's organs and, indeed, their peace of mind may depend upon knowing in some concrete fashion what has happened to those organs.

It could be objected that open acknowledgement of the donor family-recipient relationship flies in the face of an act which is publicly performed as anonymous, voluntary and altruistic. On the other hand, Renee Fox recently retired from a long academic career of sociological research on transplantation in the USA because of her concerns about the extent to which transplantation was becoming routine, "commonplace" as the UK Department of Health's 1998 promotional leaflet stated. Consequently, Fox argued,

awed respect for what is offered and taken, given and received, and accepted and rejected through this medical-surgical act is progressively eroded. (Fox 1996:260)

Conclusions and Inconclusions: Transacting Human Organs as a Moral Economy

The events of my birth ... and finally of my death are not accomplished in me or for me. The affective weight of my life as a whole does not exist for me. Only the Other is in possession of the values of the being of a given person. (Michail Bakhtin, cited in Battaglia 1990:35)

To conclude I return to the model of the 'Western person', as an autonomous and bounded individual, outlined in the Introduction to this thesis. The model is employed in anthropological analyses as an illustrative foil for 'other' economies of bodies and persons which invariably demonstrate multiplicity. Elsewhere, the person is envisaged as "fundamentally interpersonal" ((Becker 1995:4-5; cf. Kirkpatrick and White 1985:25), a site or locus of relationships (Battaglia 1990:11-12; Lieber 1990:74; Strathern 1988:13), so that "bodies do not circumscribe individual experience" (Becker 1995:5).

At the same time, Becker (1995:3) acknowledges that the "monolithic depiction" of Western persons as independent, individual and differentiated is "partially misrepresented". We are dealing with a 'folk model' not necessarily reflected in the fine grain of ethnographic investigation. My concern has been with the unreflexive deployment of this model, within academia, as an analytical tool for understanding the transacting of human tissue and organs in Western contexts. Particular attention has been given to its reinforcement of organ donation as a voluntary, anonymous and altruistic gesture.

Certainly, in the public performance of organ donation, we have caught sustained glimpses of apparently autonomous and bounded individuals voluntarily surrendering what appear to be anonymous and detached organs with no entailment of relationality. Closer consideration of the moments at which this model surfaces illuminates the politics of relationships which permeate not only the transacting of human organs but, I would argue, the ongoing process of social life within which this clinical practice is embedded. The notion of 'ownership' of one's own body, the idea that we should have the right to dispose (of) our bodies and their parts as we choose, is compelling and readily co-opted in the transplantation programme's pursuit of ever more organs. As Strathern (1996) has shown, the idea of ownership is also a powerful mechanism for manipulating the perception of connections between people. Foregrounding a potential organ donor's right to choose how his or her body parts are used after death denies connectivity with family members while simultaneously foregrounding a socially approved ethic of moral responsibility towards unknown others. Similarly, a sense of proprietorship is encouraged when human organs are, knowingly or not, treated like commodities -- detached objects which can be acquired, personalised, owned.

Though prominent and popular as political representation, the twin ideals of autonomy and boundedness foreground a jural individual as a single and impoverished aspect of personhood (cf. Ingold 1986). This model readily accords with the idea that relationships happen externally, between people, so that they can be forged or terminated with no material effect upon the people concerned. I have argued that the model of detached and autonomous individuals carries limited explanatory potential

when confronted by the kinds of personhood I found manifest in everyday, ethnographic settings in Britain.

Actual participation in the transacting of human organs, and the ongoing effects of that participation, reveals a shifting, oscillating multiplicity of bodies and persons. Accounts from donor families and organ recipients reveal a process of self-making as connective personhood, inadequately represented as the 'betweenness' of relationships conducted by autonomous and bounded individuals. I have argued that this connectivity derives from mutual participation in the tangible and intangible substance of the organ donor (cf. Helman 1991:100; Battaglia 1995:3).

Jean-Klein's (2000:) study of the 'dispersed enactment of self' has been illuminating in this regard. She notes that the notion of 'connective selves' proposed by Joseph (1994) "points at other human bodies (as well as objects) as loci where subjects make 'themselves' concrete"; thus, 'other' bodies have the potential to act as "registers of the efficacy of [one's own] subjective actions" (Jean-Klein 2000:4; cf. Becker 1995). Where the cross-bodily transfer of human organs is enacted, we have seen that the self-perceptions of all those involved can be affected by the actions of others. I have particularly amplified this effect insofar as the action, or inaction, of health care professionals and organ recipients impacts upon the ongoing production of self for donor family members, and their ongoing production of their deceased relative as a valued and generous person.

In doing so, I follow Battaglia's argument that a "critical anthropology of selfhood [must address] the problematics of self-action in their relation to issues of power" (1995:2 emphases removed; cf. Jean-Klein 2000). The donor families, and

indeed organ recipients, featured in the current study perceived themselves to be disadvantageously located vis-a-vis health care professionals who controlled their ability to demonstrate or observe, in the bodily actions of the 'other', the efficacy of their own or the organ donor's subjective action.

What I am describing here is a very different quality of self representation from that offered by the model of the autonomous, bounded individual which underpins the public performance of organ donation. Yet I have found it to resonate effectively with the notion that human organs can be more usefully regarded as a kind of property with dispersed ownership in diverse bodies. Attending to "the cross-subjective articulation of self" (Jean-Klein 2000:2) as connective personhood in the transacting of human organs also facilitates our understanding of participation in the cross-bodily transfer of organs as ongoing and open-ended for donor families as much as organ recipients. Consequently, drawing upon the anthropology of selfhood might offer an alternative to the impasse of individual rights, and the culturally unsavoury connotations of obligation, with which popular and academic discourses on Britain's transplantation programme are currently beset.

Appendix 1, Page 1

DONOR FAMILY QUESTIONNAIRE A - COLLATED RESULTS (24 returned)

Anonymity was assured. Fourteen respondents included addresses, with offers of further assistance to the researcher.

Time since death	under12 mths 3	1-3 years 12	4-5 years 5	over 5 years 3	Not clear 1
------------------	-------------------	-----------------	----------------	-------------------	----------------

Family status of donor	Child 15	Sibling 1	Spouse 7	Partner 1
------------------------	-------------	--------------	-------------	--------------

Info letter received	up to 1 mth 11	up to 3 mths 4	over 3 mths 5	No info# 1	Other* 3
----------------------	-------------------	-------------------	------------------	---------------	-------------

(# told 'not policy'; *1 gave date, possibly up to 1 mth; 1 stated 'any time I asked'; 1 gave two answers)

Recipient letters received	Yes 18+	No 5	Other 1 (second section of form not returned)
----------------------------	------------	---------	--

(+ included multi donations - letters received from some, but not all, recipients)

Donor relative responses	Not Replied 4	Replied 14	Ongoing contact 9	Met Recipient 5~
--------------------------	------------------	---------------	----------------------	---------------------

(~ recipient subsequently died. Respondent wrote "very distressing for us but I still feel the richer for knowing her.")

KEY QUESTIONS ON DONOR FAMILY QUESTIONNAIRE

'What are your views on donor families being told about the death of a recipient?'

No view expressed - 6; View not clear - 3; Info should be available - 15 (Families told - 2); Section missing - 1.

'What are your views on contact with recipient(s) via letter'

No view expressed - 3; View not clear - 1; Favourable view - 20; Section missing - 1.

'Please give reasons for not replying to a recipient's letter'

Thought it was not allowed - 2; Did not know what to say - 1; Not good at writing - 1 (physical problem)

SIGNIFICANT FINDINGS/

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SIGNIFICANT FINDINGS FROM DONOR FAMILY QUESTIONNAIRE A

Two respondents did not get information about the use of the donor's organs as they were not considered next of kin. One was the donor's mother; the donor's husband was next of kin and declined any information. The other was the donor's long term house partner (30 years); the donor's estranged sister was next of kin and would not pass on information. Two respondents initially declined information, but subsequently changed their minds.

One respondent reported serious distress about consenting to her husband's wish to be a donor, and also expressed guilt about her feelings. People do not understand why she has such negative views towards donation.

One respondent now wishes she had made the effort to reply to a recipient's letter.

Two donor family questionnaires were sent out via recipients, to their own donor's family.

Appendix 2

DONOR FAMILY QUESTIONNAIRE B - COLLATED RESULTS (32 returned)

Questionnaires distributed by the Donor Family Network. Anonymity was assured. Sixteen families replied, enclosing addresses, and offering further help to the researcher.

Time since death of donor	under 12 mths 2	1-2 years 10	3-5 years 11	over 5 years 8	
Family status of donor	Child 22	Parent 2	Spouse 5	Partner 2	
Info letter received	up to 1 mth 8	up to 3 mths 12	over 3 mths 6	No info 1	Unclear* 4

(*Respondents did not delete 'week/month')

Recipient letters received	Yes 17+	No 14
----------------------------	------------	----------

(+ included multi donations - letters received from some, but not all, recipients)

Donor relative responses	No Reply 5	Reply 12	Ongoing contact 9#	Met Recipient 6
--------------------------	---------------	-------------	-----------------------	--------------------

(#1 intends to meet)

KEY QUESTIONS

'Could you give your views on donor families being told about the death of a recipient?'

(Families told - 5)

View not clear/not expressed - 13; Favourable view - 14; Prefer not to know - 4.

'Please give your views on contact with recipient(s) via letter'

View not clear/not expressed - 2; Favourable view - 27; Prefers no contact - 2

'Please give your reason for not replying to a recipient's letter'

Prefers no contact - 1; Intends to write - 1; Reply not permitted - 1; Address excluded - 2

NB This data has been kept separate from the other study because a) the DFN has strong ties to Queen Elizabeth Hospital Transplant Unit, Birmingham, which has a policy of encouraging donor family/recipient contact, including face to face meetings and b) it maintains a reasonable balance of donor family/recipient replies in the main data. Despite the supportive atmosphere in QEH, however, group members have experience of hospital units/co-ordinators where minimum info is given out and contact not encouraged.

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DONOR FAMILY QUESTIONNAIRE sample

Please indicate how long ago your relative became an organ donor -

.... under 3 mths 3-6 mths 6-12 mths longer (..... years)

and his or her relationship to you -

SECTION A - INFORMATION ABOUT RECIPIENTS.

1) If you received information about recipients of your relative's organs, please tick -

.... age sex family status organ received

please specify any other details

* This information was given by the co-ordinator other hospital staff
 over the phone in a letter

*How long after your relative's death? Please specify number of months

Could you give your views on donor families being told about the death of a recipient?

.....
.....

2) If you received no information about recipients please tick A, B or C -

A* I was told it was the policy not to give out information

B* at the time of my relative's death, I did not want any information

If B, have you since changed your mind? YES NO

If yes, did you contact the co-ordinator to ask for information? YES NO

If you did, what happened?
.....

If you did not, can you say why not?
.....

C* any other reason given to you for a lack of information about recipients -

.....
.....

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DONOR FAMILY QUESTIONNAIRE sample**SECTION B -CONTACT WITH RECIPIENTS**

1) Have you received any letters/cards from recipients? YES NO

If NO, how do you feel about this?

2) If you received a letter/card, did you reply? YES NO

If NO, can you say why -

..... I did not know what to say I found the idea too distressing

..... the co-ordinator said it was not appropriate

..... I got the impression it was not allowed, so I did not ask

..... other reason.....

If YES, did it lead to ongoing exchange of letters or cards? YES NO

Please give your views on this sort of contact.....

3) Have you met any recipients of your relative's organs? YES NO

If YES, who initially suggested a meeting?

..... me/my family recipient co-ordinator

If NO, could you say why not?

..... it has not been suggested by anyone

..... I did not wish to meet them recipients did not wish to meet me

Any further comments

Appendix 4

RECIPIENT QUESTIONNAIRE - COLLATED RESULTS (15 returned)

Recipients who have written to their donor's family (Total 13)

Info given to recipient	None 5	On Donor 8	On Donor Family 4 (3 relationship to donor) (1 sex of surviving relative)
Did info help with writing the letter	Yes 5	No 3	
Time between transplant and letter to donor family	under 3 mths 6	3-6 mths 0	6-12 mths 4 over 1 yr 4 (1 wrote twice)
Writing letter suggested by	Recipient 7	Family member 1	Joint Decision 2 Unit staff 3
Reply received	Yes - 4	No - 9	
Result	2 ongoing contact 1 lead to meetings	1 no reply expected 8 would have liked response	
'Do you remain happy that you wrote to your donor's family?'			Yes - 13

SIGNIFICANT FINDINGS FROM RECIPIENT QUESTIONNAIRE

One transplant unit supplies a standard card for recipients to sign, containing donor's first name.
4 respondents were not sure that their letters were actually passed on the donor's family.

Recipients who have not written to their donor's family (Total 2)

Respondent No 1 - "It was at least a year before I gave the donor family a thought. Then I think it was too late."

"I think I must have shut out any thoughts of the donor family. I think I felt it was a taboo subject and that any thought of contact was out of the question."

Respondent No 2 - "I felt guilty about my donor" - questionnaire response ticked.

"I felt too sensitive to their feelings at that time, and that later it was too late. As more time passes the more I wish I had written."

TRANSPLANT RECIPIENT QUESTIONNAIRE sample

SECTION A - FOR THOSE WHO HAVE NOT WRITTEN TO THEIR DONOR'S FAMILY.

How long ago did you receive your transplant?

.... under 3 mths 3-6 mths 6-12 mths longer (..... years)

Please tick the answer (or answers) which best reflect your experience:

- 1) I did not write because
- I was too ill, and by the time I felt better it was too late to write
- I felt guilty about my donor and/or donor's family

If transplant unit staff had explained that donor families were often very grateful for letters from recipients, no matter how long after the transplant event, do you feel this might have made a difference to your decision? YES NO

- 2) I did not write because
- I did not know what to say
- I did not have enough information about the family to write a suitable letter

If you had been given help to prepare a suitable letter, would you have written it? YES NO

- 3) I did not write because
- when I asked transplant unit staff about it, they said it was not allowed
- I got the impression it was not allowed, so I did not ask

- 4) I did not write because (please give any other reason)
-
-
-

- 5) Do you now wish you had written to your donor's family? YES NO

TRANSPLANT RECIPIENT QUESTIONNAIRE sample

SECTION B - FOR THOSE WHO HAVE WRITTEN TO THEIR DONOR'S FAMILY.

How long ago did you receive your transplant?

.... under 3 mths 3-6 mths 6-12 mths longer (..... years)

Please tick the answer (or answers) which best reflect your experience:

1) Who raised the subject of writing to your donor's family?
 Recipient Member of recipient's family Unit staff

2) Who wrote the letter? Recipient Member of family

3) How much time had passed, since your operation, when the letter was written?
 less than 3 mths 3-6 mths 6-12 mths longer (.... years)

4) How much information did you have about your donor and family?
Donor age Family ages
 sex sex
 family status ... relationship to donor

Do you feel the information helped you to write a suitable letter? YES NO

5) Did the donor's family respond to your letter? YES NO

How did you feel about this?
.....
.....

6) Do you remain happy that you wrote to your donor's family? YES NO

Do you have any other comments?
.....
.....
.....



Providing Support For Patients, Carers and Families
Involved In Transplantation

THE TSN NEWSLETTER

Issue No 13, September 1999

Making donor contact should be our decision

"The majority of donor families and recipients felt that they should be allowed to decide for themselves whether or not to communicate with each other. Furthermore, each party expressed their willingness to defer to the wishes of the other."

These are two of the conclusions drawn from a small-scale survey carried out among our readers by Joni Wilson MA, of the Department of Social Anthropology at the University of Edinburgh.

Ms Wilson is conducting research into the social and emotional aspects of organ donation and transplantation with special reference to contact between recipients and donor families. The provisional findings from her questionnaire survey are reprinted below. They may indicate the need for a softening of the current policy of most health professionals which discourages contact of this sort in the interests of not distressing either of the families involved in a transplant operation.

Questionnaires were distributed by Ms Wilson between April and June 1999. The survey was not conducted to produce representative percentages or any form of randomised, or allegedly objective results. Rather, the researcher sought to elicit the personal viewpoints of transplant recipients and donor families, on certain arguments presented to her by health-care professionals working in transplantation - which were offered to support policies of minimal or no contact between donor families and the recipients of their relative's organs.

Transplant recipients were invited to respond via a letter placed in the Transplant Support Network's newsletter. Donor families were invited to respond via letters distributed by the British Organ Donor Society, (17 responses), the Coordinators at Freeman Hospital (five responses) and two recipients who made contact with their donor's family direct.

In general, the responses received to date tend to support the overall conclusions drawn from four years of research. These involved one-off and multiple open ended interviews, and many informal conversations, with health care professionals, transplant recipients and donor families. Further supporting information has been drawn from a range of bereaved people, as well as the professional and lay persons who offer services before, during and after a death.

Recipients' letters appreciated

A significant research finding was an understandable desire on the part of health care professionals to protect bereaved people from

Inside this issue:

- Page 3 - Your letters
- Page 8 - A Granny's Experience
- Page 10 - Getting what's due to you
- Page 12 - The Transplant Games
- Page 14 - Chairman's Report

The Transplant Support Network, Room 8, Temple Row Centre, 23 Temple Row, Keighley, BD21 2AH.

Office & Fax 01535 692323 Support Line 01535 210101 Registered Charity 1052328

e-mail: phatton@tsnet.demon.co.uk www: <http://www.users.zenet.co.uk/tsn/>

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distress. Specifically, this was one of the main reasons given for preventing communication between a transplant recipient and the family of his or her donor.

This survey, coupled with the long-term, intensive study of two donor families, suggests that at the very least a letter of acknowledgement can be beneficial. Of the 17 situations where a recipient's letter was received, 16 donor families expressed unequivocal appreciation and 13 of those sent back replies to the recipient.

Eight families have retained ongoing contact and four of those have met the recipients. All expressed their satisfaction with these situations.

The subsequent death of a recipient was also frequently cited as a reason for minimising the flow of information to donor families. ("Hearing of a death would be too distressing.") While the researcher cannot say donor families would not find the news distressing, she can say that 16 donor families were in favour of such information being given. Six did not express any view and one was not clear. Four families had been told of a recipient's death and were saddened, but seemed able to manage the information.

Information is wanted

A less commonly cited reason for not providing information on recipients was that "many" or "some" donor families do not want any. Only two respondents in this survey said they declined to receive details about the recipients of their relative's organs; both subsequently changed their minds. Sadly, in one other case, the donor's spouse was regarded as next of kin, and as the spouse declined to receive information, the donor's parent was also left with no details, although they would like to have received them.

The most common reason given, by transplant unit staff, for preventing or discouraging recipients from writing to their donor's family was their often overwhelming sense of guilt that they are alive as a result of the death of another person. While comments from recipients certainly included their feelings of guilt, and extreme gratitude, only two recipients had not

written to their donor's family. By the time they felt able to do so, they both thought it was too late.

In contrast, no donor family remarked that letters arrived at inappropriate times, but one recipient said staff in his unit thought writing eight months after his operation was "too soon" while the other recipient felt that writing a year after the operation was "too late".

No regrets

Of the 11 recipients who wrote to their donor's family, the suggestion to do so came from transplant unit staff in two cases, a spouse in one case, and was a spouse/recipient decision in another. No recipient regretted the decision to write. In one case, there has been an ongoing exchange of letters; in another, the recipient had met members of his donor's family. Of the nine who did not receive replies, one recipient said a reply from the donor's family was not expected, while eight would have liked a response. However, in four cases recipients said they did not even know if their letters had been passed on.

The questionnaire asked recipients if a decision not to write to their donor's family might have been different, had it been explained to them that such a letter is often very gratefully received. Both recipients who did not write said yes, this would have altered their decision.

When placed in the context of my longer term qualitative contact with transplant recipients, these findings suggest that writing to express gratitude may actually be more beneficial to recipients than leaving them with a sense of "unfinished business".

Deciding for themselves

In conclusion, the majority of donor families and recipients felt that they should be allowed to decide for themselves whether or not to communicate with each other. Furthermore, each party expressed their willingness to defer to the wishes of the other.

Thanks to all readers who volunteered information. I am particularly grateful to two of TSN's regional organisers, for their support in promoting responses (13 responses).

A practical guide for applications to medical ethics committees

Anthropology in inaction?

Joni Wilson

Doing research on sensitive subjects has generated a considerable literature within sociology and social anthropology, to which the present article can make only a modest contribution. Hopefully, it will be a useful one for postgraduates venturing into the domain of biomedical science, where medical ethics and gatekeepers combine to offer a daunting, but understandable, challenge. A brief outline of my research will serve to set the scene.

I am exploring the categories life, death, body and person - their construction, their linkages with each other, and the extent to which both can be manipulated as strategies for, and as a result of, the management of life crises and death, particularly in hospital contexts. The technical maintenance of patients in long term coma or persistent vegetative state (which could be viewed as liminal areas between life and death), and organ transplant surgery (which creates biological and social links between strangers), appeared to offer highly pertinent contexts for my research, as well as a substantial literature on the ethical and social dilemmas involved.

Getting started - patience is a virtue

Research is being conducted in Scotland, my home country, and as first year classes ended in May I was all set and raring to go at the beginning of June. It is now November, and I have set foot in hospitals six times, though my correspondence and telephone call files are pretty weighty! The first helpful comment I can offer, naive as it may seem, is to be prepared for a lengthy wait before actually getting near any patients. The reasons for this are complex and interwoven, but I shall endeavour to separate them into a few key points.

Issues of access

Generally, in anthropological research, physical access to a field location is available before one begins to negotiate social

access to potential informants. However, health care professionals have an ethical responsibility to protect patients from invasion of privacy and untoward distress, though the individual exercising of these protective roles can vary considerably - in my case from immediate agreement to access, to immediate refusal. Nevertheless, for research in hospitals, both aspects of access have to be negotiated simultaneously due to the need for ethical approval, and the requirement of Informed Consent which should be obtained from participating patients before research begins. Although I also wish to include health care professionals as informants (which does not require ethical approval), no hospital unit has allowed access for opportunistic chats with them before ethical approval has been granted.

Access to health care professionals can also be difficult. In retrospect, trying to establish contact was not assisted by my concern that any attempts to press for a prompt response from units would result in outright refusal. Health care professionals are very busy people and considering requests for research access, especially non-medical, is not a priority until formal application has been made. An application can be submitted without prior contact with selected units but it would be prudent to speak to their health care professionals first, not least because a refusal would negate the point of submitting an application! It may be necessary to contact directors of medicine and nursing at hospital level, the medical and/or surgical heads at unit level, the senior nursing sister and/or quality manager of the unit, and other relevant personnel. I also contacted chaplains (see below). I can only suggest that researchers select a first contact and ask who else should be involved. Alternatively, write to all of the above in a 'belt and braces' approach.

The location of particular groups of patients may not be readily apparent and is complicated by the fact that different hos-

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pitals have different arrangements, so precise and early inquiries should be made. Here, I admit my own discomfort with respect to asking where I would find comatose, persistent vegetative state and brain dead patients. The questions took on a vulture-like quality given the extent to which health care professionals repeatedly emphasised the sensitive nature of my research, the potential for distress to patients and their families, and their own doubts about my personal and professional qualifications for the research. To help allay these concerns, I have taken an introductory training course with a recognised bereavement counselling organisation - a substantial budgetary consideration as it cost £400.

Ethics applications - the committee

There may be a single committee for all hospitals in a region/city, or individual committees at every hospital. In the former, one has to juggle negotiations with all the hospital units and only submit when the last one has agreed, which can seriously extend the process and is very frustrating. In the latter, an application to any one committee can overlap with approved research in another, but this increases administrative work, as forms may vary in style, length and information requested. Either way, an inquiry about ethical approval in 'first contact' letters would be useful, to ascertain which system applies.

Learning from my experience, I suggest the next step is to contact the secretary to the committee and ask for the form and information on procedures (this may be on disk), deadlines for submission, and the committee meetings to which they are linked. These can be several weeks apart, and the researcher may be required to attend. Once a decision has been reached, it is sent out promptly, but further work may be necessary before approval is granted. On a practical note, be prepared for printing costs. In my case, one application costs £33, not counting several drafts, distributed to several people.

The form

This is designed for medical/scientific research and does not readily adapt to anthropological research. Information must be given in fairly basic language, as committees usually have several lay members unfamiliar with academic or technical jargon. It should describe, in a very limited word count, research purposes, aims and methods, and possibly procedures for se-

lecting and recruiting informants, as well as the benefits of the research which, in medical contexts, is expected to contribute generally to medical knowledge or specifically to patient treatment. Social research occupies a rather precarious position and a trawl through medical/nursing journals may help identify an angle of approach, as might discussions with medical or nursing personnel in teaching faculties. One might also adopt the simple expedient of asking the head of the unit for an opinion about any contribution which could be made, but be prepared for negative responses - even when gaps in social aspects of health care have been identified from within the health care professions.

Information for patients

You will be expected to submit a Patient Information Sheet (details of research purpose and methods) and a Consent Form (details of participation and withdrawal options). One A4 page for each is best - suggested formats and essential details for inclusion are usually supplied - and it may be necessary to produce different sets for patients with different medical conditions. Language should be even more basic ("about the level of a *Sun* reader" was suggested to me), but it must show sensitivity - no bald statements about dead bodies - or it may require redrafts. Patient access to an independent person may be required - someone who can give impartial advice about participating in the research. I approached hospital chaplains, who have been very supportive, but this may also involve a lengthy discussion phase since many chaplains are active in formal hospital structures for patient rights and ethical issues, which could clash with the advisory role.

The protocol

To those of us familiar with a research proposal featuring reviews of theoretical and regional literature, the Protocol is a daunting task. It involves a wider and more detailed description of the research design - structure, methods, time scale, etc. though the language should remain jargon-free. Health care professionals may ask to see the Protocol before its submission (over and above any preliminary outline), and alterations may be required. In the main, I found this most helpful though it lengthened the process even further. However, I also found it necessary to tactfully draw the line where proposed changes illustrated taken for granted assumptions about the

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very issues I want to research, for example why the word 'disposal' cannot be used for what happens to dead bodies.

Conversely, it has been an educative experience to address anthropology's taken for granted assumption - that research is carried out through participant observation in long term fieldwork - and to convert this into a reasonably precise presentation of what is to be done, when, why and how. A very helpful document, recommended to me, is listed below and it includes further reading on how to approach detailed ethnographic research design. I would also be happy to supply copies of my application documents, in exchange for copying/posting costs.

And finally...

Be prepared to encounter the sensitive issues of hospital politics and professional personalities. When working with more than one unit or hospital, maintaining locational and informant anonymity can be difficult because medical ethics and anthropological ethics suffer a lack of fit. In the former, concern is for patient anonymity in written materials; in the latter, at least for me, health care professionals are also informants entitled to anonymity. However, describing my research in a country where few hospitals deal with the medical or surgical conditions involved means that health care professionals pretty much know where I am anyway. You may be confronted with a direct "Have you spoken to Dr X at Y hospital then?" or "What did Z unit in Anytown have to say about this?". Attempting to conceal locations or people may be met with "Oh, I'll give them a ring."

Health care professionals may also have difficulty appreciating why their participating patients/family members should remain

anonymous to them. My explanation that they may wish to relate negative as well as positive aspects of their hospital experiences, for which assurances of anonymity are essential, provoked a diverse range of responses, as did the idea of my observing interactions between health care professionals, patients and family members, as they manage their experiences of life crises and death. Would I be there to criticise? The short and honest answer is "not exactly", but I may observe instances where health care professionals' actions or modes of communicating (or not communicating) information caused distress, which patients later commented on. To screen these out of my thesis would be a serious distortion. My positive counter argument, gleaned from medical and nursing literature, that health care professionals may need bereavement training and counselling support in a highly emotional and pressured environment also met with diverse responses.

My only advice here is to bear in mind that health care professionals are also people, and none of us are fond of negative criticism, especially when we feel we are doing our best. On the whole, however, I have received much positive support and interest, for which I am extremely grateful.

Joni Wilson

PhD student

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Edinburgh University*

Acknowledgement

Research is generously funded by the Economic and Social Research Council.

Reading

Scottish Consensus Statement on Qualitative Research in Primary Health Care (1995), J Dowell, G Huber and C Smith (eds)
Tayside Centre for General Practice, University of Dundee,
Charleston Drive, Dundee DD9 2 4AD
01382 632771 Cost £5.00

Anthropological research in hospital settings

Paths to a quagmire?

Joni Wilson

MY initial article on applications to Medical Research Ethics Committees (RECs) appeared in Volume 4, Issue 1. What follows is an update, which should be read in conjunction with the earlier article.

As my original article stated, the second half of 1996 was spent in approaches to, and discussions with, health care professionals in selected hospital units, where I wished to speak to staff, patients and relatives. During the course of 1997, I was able to submit three applications to RECs, two of which were rejected and went through an appeal procedure. This involved long and rather gruelling interviews with the REC concerned. Approval was not granted in either case and, while appeals can be made indefinitely, my own time restrictions eventually impinged, as work on appeals detracted from research in other contexts. I also frankly admit that I just got tired of it all. The whole process was very time consuming and frustrating.

While it is not my intention to imply that RECs are deliberately obstructive, or that all anthropological research is rejected simply because it is anthropological, I maintain the view that anthropological methodologies offer particular problems for RECs - and that ethics applications offer the same for anthropologists! That there is a lack of fit between anthropological and medical/scientific research is apparent from the design of application forms, as my original article stated. It

was also emphasised in the letters of rejection which I received. One committee stated (after the appeal) that my research had no evident scientific or measured outcome to assess against base data, and the other (prior to the appeal) that the research lacked structure and definition. Despite substantial work on the applications and appeals, and lengthy discussions with both Committees, I was unable to convince them that my apparently 'vague' and 'woolly' methods could produce valuable data. On this point, it should be noted that the value of research is judged in terms of benefit to particular patients, or to medical knowledge generally. The lone anthropological researcher is not on firm ground here.

Before proceeding further, I must acknowledge the strong opposition to my wish to speak to bereaved relatives of patients declared brain dead, which emerged during the negotiation and application process. The sensitivity and potential distress of this aspect of my research was constantly emphasised, despite a considerable literature which argues that bereaved people may be desperate for someone to talk to about their loss. This issue formed the bulk of discussion at the appeal interviews, but I cannot say to what extent it influenced the final decisions of RECs. In one case the issue was not mentioned in the formal letter of rejection, and in the other I have not yet received formal notification with details of specific objections. Nevertheless, it is possible to extricate some general comments from my particular circumstances.

Should an application to an REC prove necessary, it may

help to bring a clinical consultant on board as a supervisor, or 'member of the research team'. Application forms provide for a research team, though I misunderstood its implications. It can be used as a nominal designation and does not imply joint thesis production, but does add clinical 'clout'. Conversely, even senior consultants meet with rejections, so it is no guarantee, but it may support arguments about the value of the research.

Some unit staff and REC members were extremely uncomfortable with anthropology's standard approach of 'just talking' to people. They wished to know exactly what I would ask, despite my assertion that this would impose an agenda on informants. However, I admit my own disciplinary purism got in the way, as I struggled to defend anthropology's open-ended, conversational approach.

Researchers may therefore find it useful to provide an innocuous questionnaire for the REC, since there is clearly a demand for, and understanding of, this method. If access is granted, no-one can tell or prevent what else may arise in the course of administering it, but some caution is required if what is actually being done differs from the application submitted. Significant alterations to the project during the period of access have to be referred back to the REC. On the other hand, once contact has been established, it can extend beyond the period of access to a unit. While all medical or scientific research, even involving healthy volunteers from the general public, has to be submitted for ethical approval, RECs have no control over social research involving people who happen to have experience of a hospital admission - their own or someone else's.

For this reason, and unless direct observation is essential, I would say avoid the need for ethical approval entirely. Hospital politics and administrative structures, and the process of application and appeal, appeared to me to be a quagmire into which I was being irresistibly drawn, never to return! Avoidance may depend on one's initial contacts. I approached unit staff who were of the opinion that the research required ethical approval. All the REC Secretaries I then contacted were of the same opinion. However, a recent chance encounter with a large display about quality management, located in a hospital foyer, led me to contact the manager himself. He and his colleagues held that the research was not clinical, and therefore did not need ethical approval. I was told that there is a great demand for qualitative research on the subjective experiences of hospital patients and their relatives, but a lack of funding and/or time to conduct it. Independently funded PhD research could offer a possible solution. I have also recently learned that 'audit' research does not require ethical approval. Researchers may therefore find it more fruitful to make initial approaches to quality managers, research and development managers, or clinical audit managers, rather than unit staff who are more used to conducting research which does require ethical approval.

There is a second option. In my original article I stated that hospital units were reluctant to allow access to staff until ethical approval was given. However, this is not required where staff, rather than patients, are involved and I eventually persuaded one unit to let me contact a selection of staff, whom I met in the unit. Once into a unit, researchers would have access to notice boards which often display information about out-patients' support groups, where they exist, which is a further avenue for contact. Conversely,

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some groups may be equally unwilling to facilitate introductions, as I discovered in one case. A further difficulty arises if the group meets on hospital premises. If a researcher attends meetings, this is, strictly speaking, access to patients in NHS premises - which requires ethical approval.

A third option which occurred to me was to place notices in the press, asking for help. The level of response may depend on the clinical condition being researched. In my own case, for example, there are very few organ recipients as a percentage of the population, and they are very dispersed, geographically. Several attempts might be needed but such a method of contact would in all probability be cheaper, less time consuming, and ultimately more successful than REC applications.

The final option, to which I was seriously tempted, is to conduct research on RECs themselves. My experiences will

form part of my thesis. Indeed, they are central to it since I found that it was health care professionals, rather than bereaved people, who held that death is too distressing to talk about. Nevertheless, as a means to a beginning - contact with patients and their relatives - I had to abandon the process. As a means to an end, pursuing an application would offer the opportunity to study, in depth, the subjective foundations and workings of RECs - an intriguing project in itself.

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Acknowledgement

Research is generously funded by the Economic and Social Research Council.

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